# Exploring the cognitions and behaviours associated with vasomotor symptoms (hot flushes and night sweats) in men with prostate cancer undergoing hormone treatment

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# VOLUME I:

## MAIN PROJECT AND SERVICE EVALUATION

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# A C K N O W L E D G E M E N T S

First and foremost I would like to thank all of the men who participated in this study for sharing their experiences with me and for allowing me a small window into their lives with flushes. I have attempted to capture the essence of each and every experience and hope that no man's voice is lost in the accounts that have been given.

I would like to express my gratitude to my research supervisor Professor Myra Hunter whose expert knowledge and continuous guidance and encouragement have been invaluable. Alongside this, her support and enthusiasm have been both motivating and inspiring. I hope this study provides a meaningful contribution to her ongoing and dedicated work exploring hot flushes and night sweats and developing cognitive behavioural interventions to manage these symptoms. I would also like to thank Dr Alex King who was able to step in when necessary, allowing this study to go ahead. Special thanks are extended to Dr Elizabeth Grunfeld, who made the time to review and comment on study design and thesis drafts despite her move to Birmingham University. I am extremely grateful for her devotion and continued support.

Finally, I would like to thank my family and friends for their patience and constant optimism and faith in my abilities, even when my own was lacking. I would like to thank my mother for being my inspiration, my sisters Adanna and Ndidi, my brother Kenechi, my father and my uncles Chinedu and Obi for keeping me motivated over the past three years and Steph and Sunit for thinking of me and for their kind words as I was nearing the "final stretch". I would particularly like to thank Adanna, who gave me the time and space I needed when I was writing-up, my best-friend Hayley, who put everything aside and was always there for me when I needed her and my boyfriend Oliver who has done all of the above, and more, and has been incredibly patient and understanding over the past few months. Of course I must also thank all of my course colleagues who through their presence, energy, humour and camaraderie helped me to reach this point.

# MAIN PROJECT:

# Exploring the cognitions and behaviours associated with vasomotor symptoms (hot flushes and night sweats) in men with prostate cancer undergoing hormone treatment

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## A B S T R A C T

*Objectives:* Hot flushes and night sweats (HF/NS) in menopausal women are well-documented; psychological measures and interventions for managing these symptoms have been developed for women. Experiences of HF/NS in men with prostate cancer, which occur due to hormone treatment, are currently under-researched. Thus, this study involves a preliminary qualitative exploration of HF/NS cognitive appraisals and behavioural reactions reported by a sample of these men. Black men of Afro-Caribbean descent, white British/English and Irish men were included in order to consider possible differences relating to ethnicity.

*Methods:* Semi-structured, in-depth interviews were conducted with 19 men (14 white British/English, 1 white Irish and 4 black British) who were receiving hormone treatment for prostate cancer and experiencing HF/NS. Framework analysis was used to explore HF/NS experiences, generate and categorise emergent themes and explore associations between themes.

*Results:* Ethnicity-related thematic analysis was limited by the small sample of black British men recruited. However, analysis across all men identified a core superordinate theme labelled 'cognitions about HF/NS', along with eight other themes. There were men who held beliefs about the impact of HF/NS on their masculinity, experienced shame and embarrassment due to concerns about HF/NS salience and perceptions by others and experienced feelings of powerlessness over HF/NS; powerlessness was associated with beliefs about the fatal consequences of discontinuing treatment. Cognitive appraisals (e.g. those associated with perceived control and embarrassment) influenced subsequent coping strategies. Thematic findings supported those identified in previous literature exploring HF/NS in male and female populations. Novel themes highlighted possible influences on HF/NS experiences, including beliefs associated with prostate cancer, general self-perceptions and potential socio-cultural influences.

*Conclusions:* A range of men's cognitive-behavioural experiences were generated from this qualitative exploration. An index of cognitive-behavioural themes was generated which could be used to inform future research into this under-researched field.

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# Chapter 1: INTRODUCTION

Vasomotor symptoms or hot flushes and night sweats are the result of thermoregulatory instability which can be triggered by a number of physical and/or emotional conditions (Moyhi *et al.*, 1997). The perceived severity of hot flushes can vary from individual to individual and in extreme cases can result in disabling consequences (Kronenberg, 1990).

The research literature regarding hot flushes has been widely studied in women. The reason for this being that flushes are common physiological consequences of the hormonal changes associated with the menopause (Kronenberg, 1990; Hunter & Liao, 1995); they can be an indicator of the onset of the menopause, alongside the gradual cessation of menstruation and other physical and emotional changes. However these symptoms are also common, but less extensively researched, in men with prostate cancer who experience hot flushes as a side-effect of hormone therapy to treat prostate cancer (Stearns *et al.*, 2002). One of the few studies exploring men's experiences of flushes includes a qualitative investigation by Grunfeld et al., (2012), which considered a range of side-effects of hormone treatment, of which flushes were one.

Given the distress that hot flushes can cause, research studies have identified a variety of treatments that have been found to effectively manage these symptoms, including medication (Adelson *et al.*, 2005) and psychological interventions such as cognitive-behavioural therapy (Hunter, 2003). Many of these treatments have been explored in both male and female populations and there are recommended clinical guidelines for the pharmacological treatment of hot flushes in men with prostate cancer. However, psychological interventions that have been identified as effective in women have not been considered in men who also experience hot flushes. Psychological interventions emphasise the significance of interactions between thoughts, feelings and behaviours in the maintenance of unhelpful cycles which could influence emotional reactions to hot flushes, the extent to which they are detected and perceived as problematic and the coping strategies that are enlisted to manage them; for example Hunter's (2003)

cognitive-behavioural model of premenstrual problems and menopausal hot flushes and Hunter and Mann's (2010) cognitive model of hot flushes and night sweats.

This study qualitatively explores the experiences of hot flushes and night sweats in men with prostate cancer, whereby emergent cognitive and behavioural themes were identified and analysed in order to establish the ways in which such themes interact to influence perceptions of hot flushes and night sweats in this population. The following sections of this chapter provide an overview of prostate cancer, recommended hormonal treatments for prostate cancer and their mechanisms, an introduction to hot flushes and night sweats, including their pathophysiology and treatment and a review of the relevant literature associated with the cognitive-behavioural experiences of hot flushes, illness cognitions and health behaviour. Following a summary of the literature, the rationale for this study is also described and research aims and questions are highlighted.

## *1.1 Prostate Cancer*

The prostate gland naturally increases in size as men age (Rhodes *et al.*, 1999) thus cell growth in this region is not uncommon. Prostate cancer is diagnosed when this cell growth becomes unregulated and begins to spread to other regions of the body.

### 1.1.1 Prevalence

Prostate cancer has the highest diagnostic incidence of all cancers in males in the United Kingdom (Cancer Research UK, 2010) and in wider Europe (Ferlay *et al.*, 2007). Over the last 30 years prostate cancer rates in Great Britain have almost tripled and this form of cancer was reported in 40,841 men in the UK in 2009, whereby the crude incidence rate is 135 cases per 100,000 men (Cancer Research UK, 2010). Prostate cancer is the second most common cause of cancer-related deaths in men, with 12% of all cancer deaths in men in 2007 attributable to prostate cancer (Cancer Research UK, 2010).

Increased awareness of prostate cancer and early detection methods for diagnoses, such as testing for serum markers like prostate-specific antigen (PSA) and the use of biopsies, are thought to have contributed significantly to its increased incidence (Frisk, 2010; Bostwick *et al.*, 2004). These factors have also played a role in reducing the number of deaths resulting from prostate cancer (Denmeade & Isaacs, 2002) for example, death rates in the UK peaked in the early 1990s (Collin *et al.*, 2008), and have since fallen by around 20% (Cancer Research UK, 2010).

### 1.1.2 Aetiology / Risk factors

There are a number of risk factors associated with the occurrence of prostate cancer however these tend to be generated from epidemiological research which provides frequency data but overlooks the aetiological complexity of any possible trends (Bostwick *et al.*, 2004). Thus, a clear aetiology for prostate cancer remains unknown and there is no conclusive evidence to support the development of preventative measures.

Risk factors which have been reliably identified include: age, ethnicity and familial diagnoses/family history (Bostwick *et al.*, 2004: Pienta & Esper, 1993; Quinn & Babb, 2002). There is evidence to suggest that the risk of prostate cancer increases with age (Muir *et al.*, 1991; Quinn & Babb, 2002; Sakr *et al.*, 1996), that this risk is higher in men from Afro-Caribbean descent in both in the USA (Greenlee *et al.*, 2000; Sakr *et al.*, 1996) and in the UK (Ben-Shlomo *et al.*, 2008; Jack *et al.*, 2007) and that there is an increased likelihood of being diagnosed with prostate cancer if a relative also has a diagnosis (Johns & Houlston, 2003).

### 1.1.3 Treatment

Treatment options for prostate cancer vary dependent on the stage of progression and the grade of the cancer, both of which are used to establish prognosis. Stage is determined by the extent to which the cancer has spread and grade by PSA levels and

the use of the widely known Gleason system (Gleason, 1966), which involves consideration of the histological arrangements of cancerous cells in order to determine the likelihood of spread. Gleason scores range from 2 to 10 and a higher score is associated with an increased likelihood of cancerous spread; the score is directly related pathological stage and factors such as tumour size and metastasis to lymphvascular regions and other organs (Humphrey, 2004).

| | | Cancer Stage (1-4) | | |
|---|---|---|---|---|
| | | **Localised (1-2)** | **Locally advanced (3)** | **Metastatic (4)** |
| **Risk Level (Gleason score)** | **Low (<6)** | WW, AS | PR (if risk of pelvic lymph node involvement) or RR with neoadjuvant and concurrent HT (using LHRHa) for 3-6 months and adjuvant HT for 2 years minimum | Continuous HT or BO |
| | **Intermediate (7)** | WW, AS or RT or RR with adjuvant HT for 2 years minimum | | |
| | **High (8-10)** | RT or RR with adjuvant HT for 2 years minimum | | |

WW = Watchful waiting; AS = Active surveillance; RT = Radical treatment; HT = Hormone therapy; PR = Pelvic radiotherapy; RR = Radical radiotherapy; BO = Bilateral orchidectomy (surgical removal of both testes); LHRHa = Luteinising hormone-releasing hormone agonists

**Table 1.1: NICE (2008) recommended treatments for prostate cancer by stage and risk level**

According to National Institute for Health and Clinical Excellence (NICE) guidance (2008), the standard treatments for prostate cancer include watchful waiting and active surveillance, radical treatments such as radical prostatectomy (surgical removal of the prostate) or radical radiotherapy with hormone therapy. Treatment recommendations exist for four stages of prostate cancer which are grouped into three categories: localised, locally advanced or metastatic. Each stage has three risk levels for reoccurrence, low, intermediate or high; these are determined by clinical

grade. Table 1.1 illustrates NICE (2008) recommendations for each stage and risk level of prostate cancer.

Radical radiotherapy with hormone therapy is highly recommended in order to control prostate cancer with increasing risk and at advancing stages. Such treatments can be used instead of radical treatments or following unsuccessful radical treatment. Although radical treatments are considered advantageous because of improved convenience and treatment adherence for those men who have such procedures, they are irreversible and come with their own risks (NICE, 2008), thus some men may prefer a less invasive hormone therapy.

### 1.1.4 Hormone treatments and mechanisms

The role that hormones play in the maintenance of prostate cancer was identified in early research by Huggins and Hodges (1941, 1972). Hormonal therapies have contributed significantly to prostate cancer treatments since the discovery that the biochemistry of cancerous cells in the prostate could be influenced via the manipulation of steroid hormones such as testosterone. Steroid hormones are responsible for the maintenance and development of masculine characteristics and are also known as androgenic hormones or androgens.

Medical castration with oral oestrogen and other early treatments for prostate cancer were identified by Huggins and colleagues (Huggins & Clark, 1940; Huggins & Hodges, 1941, 1972; Huggins & Stevens, 1940; Huggins *et al.*, 1941); these are no longer used due to the risks associated with cardiovascular events, however the mechanisms by which they function are very much the same (i.e. the reduction or elimination of androgenic hormones). This is a mainstay of prostate cancer treatment, whereby current hormone therapies use hormones, or drugs that mimic hormones, to reduce androgenic activity (principally testosterone) via interference with the cycle of androgen production. These treatments have been associated with reductions in disease progression and increases in survival advantage (Byar & Corle, 1988; Kumar *et al.*, 2006; Medical Research Council Prostate Cancer Working Party Investigators Group, 1997; Pilepich *et al.*, 2005).

Androgenic manipulation as a method for treating prostate cancer in the UK occurs by two methods; (a) androgen withdrawal and (b) anti-androgen treatment (NICE, 2008). Each can have differing side effects and thus can impact on quality of life (QoL) in different ways:

(a) Androgen withdrawal treatments involve a reduction in the supply of androgens either surgically (e.g. radical treatments) or pharmacologically via the use of luteinising hormone-releasing hormone agonists, known as LHRHa (NICE, 2008). LHRHa reduces the production of androgens such as testosterone by preventing chemical signals from activating the production of luteinising hormone, which would ordinarily stimulate the production of testosterone (Denmeade & Issacs, 2002; Garnick, 1997).
(b) Anti-androgen treatment involves the use of medication (e.g. Bicalutamide) that reduces the effect of androgens by blocking biochemical signals, preventing the signals that promote cell division, growth of prostate tissue and inhibition of cell death from being active (Garnick, 1997).

Combination treatments (i.e. concurrent androgen withdrawal and anti-androgen treatments) are not recommended as first-line treatment due to limited evidence of its effectiveness (NICE, 2008) but can be used (e.g. maximal androgen blockade, the combined use of LHRHa and anti-androgen treatment).

### 1.1.5 Effects of hormone treatment

Robust evidence exists for the side-effects associated with androgen withdrawal and anti-androgen treatments. Side-effects include vasomotor hot flushes (Charig & Rundle, 1989; Rosenberg & von Eschenbach, 1990; Sarosdy *et al.*, 1999; Spetz *et al.*, 2001), weight-gain (Smith *et al.*, 2002), emotional distress, loss of energy and fatigue (Herr & O'Sullivan, 2000), a decrease in bone mineral density (Daniell *et al.*, 2000), loss of sexual drive and pelvic pain (Sarosdy *et al.*, 1999), gynaecomastia (Dobs & Darkes, 2005), mastalgia, diarrhoea and other gastrointestinal symptoms, abnormalities in liver function, pulmonary toxicities, alcohol intolerance and visual side-effects such as delayed adaptation to darkness (Macleod, 1997).

Vasomotor hot flushes are a highly reported symptom of hormone treatment (Schow *et al.*, 1998), whereby they can persist following the termination of therapy (Schow *et al.*, 1998; Spetz *et al.*, 2001). According to Spetz, Zetterlund *et al.* (2003), some men treated for prostate cancer report that hot flushes are the most distressing side-effect of treatment; up to 55% of men have been found to report distress caused by these symptoms and 11% report severe distress (Spetz *et al.*, 2001). Some men have been found to discontinue their hormone treatments due to frequent hot flushes that are judged to be debilitating (Frisk, 2010).

## *1.2 Vasomotor Symptoms*

### 1.2.1 Definition

A hot flush is defined as 'a sudden sensation of heat over the face, neck and chest, and may be accompanied by patchy flushing of the skin' (Spetz *et al.*, 2001, p.517). They tend to persist for 2 to 4 minutes (Dalal & Zhukovsky, 2006), although experiences vary across individuals and some report flushes lasting for more than 15 minutes (Kronenberg, 1990). Flushes are often associated with excessive perspiration, palpitations, shivering, anxiety and irritability (Kronenberg, 1994). Some individuals also report experiencing night sweats, which are hot flushes that occur during the night and cause sleep disturbances (Sievert *et al.*, 2006; Woodward & Freedman, 1994).

Vasomotor symptoms are any experiences which cause the constriction or dilation of blood vessels close to the skin and result in changes in skin temperature and conductance; they are hot flushes and night sweats and will be referred to as HF/NS where considered jointly in this paper.

### 1.2.2 Pathophysiology

Vasomotor instability causes HF/NS, whereby a disruption of the homeostatic thermoregulatory centre of the hypothalamus which controls heat loss and

conservation mechanisms leads to exaggerated activation of the body's cooling responses such as evaporative cooling via perspiration and vasodilation. This heat loss is then followed by the activation of the body's heat conservation responses such as vasoconstriction and heat production via shivering as the thermoregulatory system attempts to compensate for the heat loss (Kronenberg, 1994; Deecher & Dorries, 2007).

The precise mechanisms involved in the pathophysiology of HF/NS are unclear (Kronenberg, 1994; Mom *et al.*, 2006). However, there is increasing evidence to suggest that gonadal hormonal changes could be implicated (Casper & Yen, 1985; Deecher & Dorries, 2007) as well as other endocrinological and neuroendocrinological changes (Kronenberg, 1994; Mom *et al.*, 2006). A common theory is that the dynamic reduction or sudden deprivation of sex hormones alters the function of brain neurotransmitters such as serotonin, noradrenalin and beta-endorphins, which in turn leads to the disruption of the thermoregulatory system (Frisk, 2010; Kouriefs *et al.*, 2002); this theory has been supported by evidence demonstrating the effectiveness of treatments for HF/NS that target these neurotransmitters (Stearns *et al.*, 2002).

### 1.2.3 Psycho-social factors

Hot flushes can be influenced by psychological factors such as emotional stress and anxiety in postmenopausal women (Swartzman *et al.*, 1990) and in populations other than menopausal women, including those with psychiatric disorders (Moyhi *et al.*, 1997). The neurotransmitters thought to be involved in thermoregulatory changes are also implicated in mood regulation through similar actions (Stearns *et al.*, 2002), thus it is plausible that changes in mood could influence the thermoregulatory system via the actions of these neurotransmitters.

In addition to psychological influences, lifestyle factors such as daily alcohol consumption and smoking have also been linked to increased incidences of hot flushes in middle-aged women (Sievert *et al.*, 2006) and in individuals diagnosed with medical conditions other than the menopause (Moyhi *et al.*, 1997). Similarly, a reduction in the consumption of certain substances such as spicy foods and caffeine has been linked to

reductions in the severity and frequency of flushes in women (Sturdee, 2008). Environmental factors such as hot or humid weather or being in confined spaces have also been implicated in menopausal women (Kronenberg, 1990; Williams *et al.*, 2008). However, hot flushes also occur spontaneously and this often the case with night sweats (Kronenberg, 1994).

### 1.2.4 Biological factors: Menopause

HF/NS are one of the main symptoms experienced by women when they are going through the menopause (Hunter & Liao, 1995; Kronenberg, 1990). The occurrence of hormonal changes during menopause, including reductions in oestrogen and increases in pituitary gonadotrophins, coincides with the occurrence of HF/NS (Mom *et al.*, 2006) and this is thought to be linked specifically to oestrogen withdrawal (Casper & Yen, 1985).

### 1.2.5 Biomedical factors: Women with breast cancer

Chemotherapy can precipitate the menopause in premenopausal women with breast cancer (Hoda *et al.*, 2003; Mom *et al.*, 2006) and the most prominent side effect for pharmacological treatments for breast cancer, such as Tamoxifen, is HF/NS (Love *et al.*, 1991; Loprinzi *et al.*, 2000; Hunter, Coventry, Mendes *et al.*, 2009). There is evidence to suggest that the incidence and severity of HF/NS in postmenopausal women treated for breast cancer is greater than in healthy postmenopausal women (Carpenter *et al.*, 1998; Mom *et al.*, 2006).

### 1.2.6 Biomedical factors: Men with prostate cancer

As described previously, HF/NS also occur in men with prostate cancer following hormone treatments that manipulate bodily androgen levels or androgenic processes (Spetz *et al.*, 2001), which further indicates the role of gonadal hormonal changes in

the pathophysiology of hot flushes. The rapid reduction or elimination of androgens such as testosterone could lead to subsequent biochemical processes that affect the thermoregulatory system, thus leading to HF/NS (Frisk, 2010; Kouriefs *et al.*, 2002).

The incidence of HF/NS in men with prostate cancer for those undergoing androgen withdrawal treatments is at approximately 67% with the use of LHRH agonists (Sarosdy *et al.*, 1999) and 79% with bilateral orchidectomy (Charig & Rundle, 1989). Total androgen ablation via combined androgen withdrawal and anti-androgen treatments has been shown to produce an incidence of 74.3% of HF/NS (Spetz *et al.*, 2001).

The distress resulting from HF/NS in men is well-documented due to the clinical monitoring of side effects; they can significantly reduce QoL (Dalal & Zhukovsky, 2006; Kouriefs *et al.*, 2002; Nishiyama *et al.*, 2004), whereby disruption to sleep, daily activities and life enjoyment capabilities have been reported (Kagee *et al.*, 2001). There is also evidence to suggest that the presence of HF/NS in men undergoing hormone therapy for cancer slows the rate of decline in cancer-related distress (Ulloa *et al.*, 2009).

### 1.2.7 Treatments for hot flushes

According to NICE guidance for prostate cancer treatment (2008), the first-line treatment for HF/NS that cause significant distress is parenteral or oral pharmacological treatment with synthetic hormones, known as progestogens, such as progesterone, megestrol acetate and medroxyprogesterone. Both progestogens and oestrogens such as diethylstilbestrol, have been found to be effective at reducing the incidence of HF/NS in men treated with hormonal therapy (Atala *et al.*, 1992; Loprinzi *et al.*, 1994; Langenstroer *et al.*, 2005; Gerber *et al.*, 2000). National Health Service (NHS) guidance for menopausal women suggests the prescription of Hormone Replacement Therapy (HRT) or Tibolone to manage a number of menopausal symptoms, including HF/NS (Royal College of Obstetricians and Gynaecologists, RCOG, 2004), and guidance for HF/NS as a result of early menopause in women with breast cancer suggests the use of non-hormonal treatments (e.g. Selective Serotonin

Reuptake Inhibitors, SSRIs) depending on the cancer treatment being used (NICE, 2009).

Several other possible treatments for HF/NS have been investigated (Stearns *et al.,* 2002). For example, there are studies that suggest the effectiveness of non-hormonal treatments including the use SSRIs in menopausal women (Gordon *et al.*, 2006) and in men with prostate cancer (Naoe *et al.*, 2006), acupuncture in male and female cancer patients (Filshie *et al.*, 2005; Hammar *et al.*, 1999), aerobic exercise in menopausal women (Daley *et al.*, 2009) and naturally occurring remedies such as black cohosh and soya in menopausal women (Kronenberg & Fugh-Berman, 2002). However, these treatments have not been specifically recommended for men with prostate cancer due to the limited reliability of findings (NICE, 2008).

Psychological treatments to manage HF/NS are not mentioned in NICE guidance for treating prostate cancer (2008), nor are they mentioned in guidance for menopausal women (RCOG, 2010) or women with breast cancer (NICE, 2009). However, there is evidence that psychological processes are implicated in the maintenance of HF/NS in women (Allen *et al.*, 2006; Ayers *et al.*, 2012; Hunter, 2003; Hunter *et al.*, 2011; Hunter & Liao, 1995; Hunter & Mann, 2010; Hunter, Coventry, Hamed *et al.*, 2009; Mann *et al.*, 2012; Keefer & Blanchard, 2005; Reynolds, 1997, 2002).

## *1.3 Hot flushes and night sweats: Cognitive appraisals and behavioural reactions*

### 1.3.1 The cognitive model of hot flushes and night sweats

Hunter and Mann (2010) have devised a cognitive model of HF/NS which applies to menopausal HF/NS. It aligns physiological aspects of HF/NS (e.g. biological factors and environmental influences) with psychological processes (both cognitive and behavioural) purported to maintain them. The model, illustrated in figure 1.1, outlines the interactions between four processes involved in HF/NS experiences: (a) information input, that is, the biochemical changes and triggers that initiate HF/NS; (b) detection and attribution, that is, the perception of biochemical changes and causal

attributions for their onset; (c) cognitive appraisals associated with HF/NS, and (d) behavioural reactions to them.

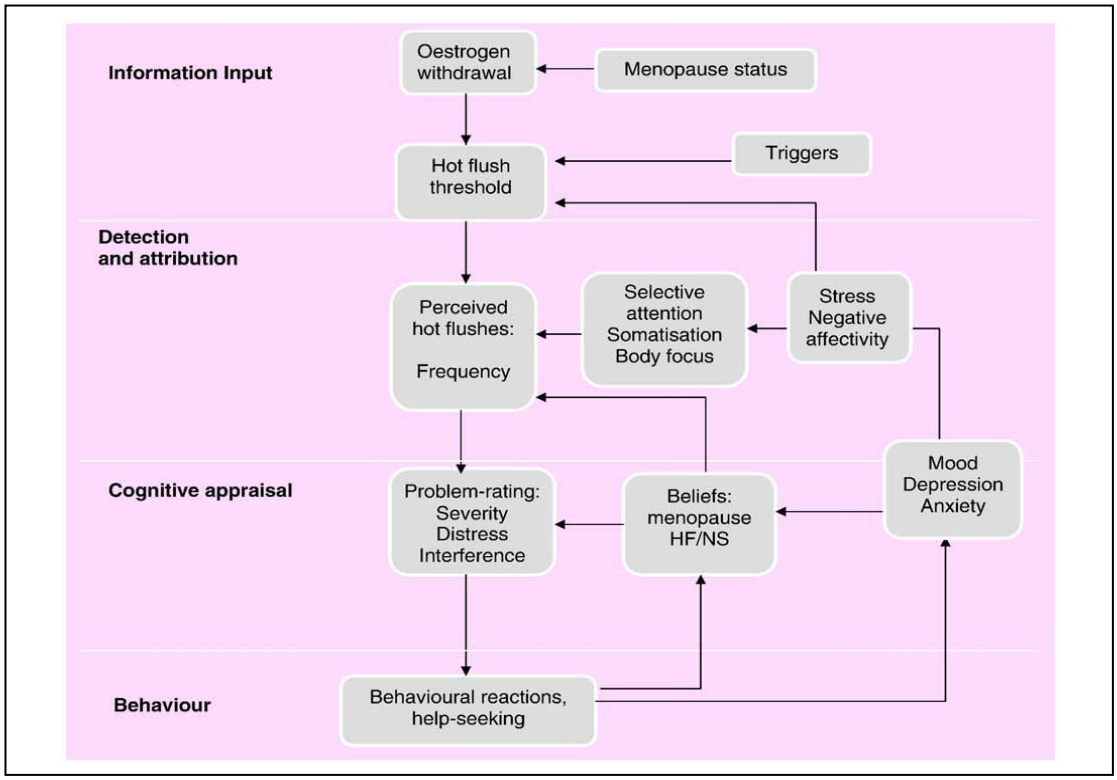


**Figure 1.1: The cognitive model of hot flushes and night sweats (Hunter and Mann, 2010)**

According to Hunter and Mann's (2010) cognitive model, oestrogen withdrawal triggers HF/NS via biological mechanisms, which have been outlined in section 2.2.2 of this paper. It has been proposed that, in symptomatic menopausal women, the thermoregulatory system is disrupted by rapid hormonal change such that thresholds for flushing and shivering are altered (Freedman & Krell, 1999; Freedman, 2005, 2009). These thresholds define the thermo-neutral zone, which becomes narrowed and therefore sensitive to variations in body temperature (Freedman, 2005, 2009). This means that HF/NS may be triggered by slight increases in environmental temperature and may also be potentiated by stress and anxiety and triggered by a variety of other factors such as intense exercise, hot drinks and spicy foods (Hunter & Mann, 2010).

Following a biological trigger, HF/NS are experienced. The model suggests that the perception of HF/NS could be influenced by attentional bias towards internal bodily

signals or somatisation (where this bias leads to attributions of internal states to physical causes), for example, when there is a poverty of external information (Hunter & Mann, 2010). Thus, among those who might have a tendency to focus on bodily symptoms (symptom amplification), the likelihood of perceiving HF/NS may increase due to the hypersensitivity to internal bodily changes (Hunter & Mann, 2010). The extent to which factors, such as selective attention and bodily focus, influence the detection of HF/NS is subject to individual differences and the cognitive model suggests that these factors may be influenced by negative affectivity (a tendency to experience and report negative mood), which is associated with an increase in the awareness and reporting of symptoms due to a lower threshold for the detection of physical sensations states (Hunter & Mann, 2010; Watson & Pennebaker, 1989).

Mood and cognitive representations of HF/NS are thought to influence the perception of them via differing routes; mood via the effects of stress and negative affectivity (described above), and cognitive representations via the effects of cognitive appraisals and emotional reactions. According to Hunter and Mann (2010), although the model separates the HF/NS detection process from the cognitive appraisal process, there is likely to be an interaction between mood, beliefs about HF/NS and the menopause and HF/NS reporting that is more complex than the model suggests. However, the authors propose that mood influences cognitive representations about HF/NS and the menopause, which in turn influence the extent to which HF/NS are perceived as problematic (in terms of severity, distress and interference); these cognitive representations are also thought to affect perceptions of HF/NS frequency.

The cognitive model suggests that behavioural reactions, including treatment- or help-seeking, are directly influenced by cognitive appraisals relating to how problematic HF/NS are. These behavioural reactions also feedback into the model via the influence they have on mood and cognitive representations of HF/NS and the menopause; where a behavioural reaction is effective, for example, this may influence beliefs about the extent to which HF/NS can be self-managed and may improve mood. This feedback creates a closed-system in which the four processes of HF/NS experiences are linked.

Thus, it seems that cognition representations of HF/NS may play a fundamental role in the frequency with which they are perceived and the degree to which they are

perceived to be problematic; behavioural reactions also seem to be influenced by such appraisals and may impact upon them. It is possible that the four processes described in the cognitive model of HF/NS (information input, detection and attribution, cognitive appraisal and behaviour) may be applicable to men who experience HF/NS as a side effect of hormone treatment for prostate cancer, whereby these men may be subject to the cognitive and behavioural influences on HF/NS. There would, however, be a need to consider the fundamental differences between this population and the population for whom the model was originally intended along several dimensions. For example, the specific biological mechanisms that result in HF/NS are different for men with prostate cancer; they relate to a change in androgenic hormone levels rather than oestrogen withdrawal. Similarly, appraisals or beliefs about HF/NS are likely to relate to prostate cancer and hormone treatment rather than the menopause.

### 1.3.2 Cognitive influences in men with prostate cancer: The role of illness representations

There is limited research considering cognitions relating specifically to HF/NS in men undergoing treatment for prostate cancer. However a large body of research exploring dimensions of illness representations and the ways in which these interact with health behaviours, coping and illness outcomes does exist; cognitive representations of prostate cancer have been considered in terms of these dimensions (Traeger *et al.*, 2009). Cognitive appraisals about prostate cancer and related problems, in the form of illness representations, may play a role in influencing general emotional and behavioural reactions to prostate cancer and shaping general appraisals about how problematic the disease is. These general appraisals and reactions implicitly include problems such as treatment side-effects and therefore could also shape and influence cognitions and behavioural reactions about HF/NS.

Leventhal *et al.*'s (1992) self-regulation model (SRM), also known as the common sense model, of illness representations and the perceived threat posed by illness is outlined in order to demonstrate the structure of illness representations and the interactions between cognitions and behaviours about illness. This model has been

selected as it goes beyond other theories of health behaviours by integrating the multiple factors that influence these behaviours (Diefenbach & Leventhal, 1996). Leventhal *et al.*, (1992) propose that there are two psychological processing systems that produce illness representations; one system creates an objective representation, with its own coping strategies and cognitive appraisals for managing perceived illness, and the other creates a subjective or emotional representation, with parallel coping and appraisals for managing emotions. The SRM, illustrated in figure 1.2, shows the way in which environment (socio-culture context) and individual characteristics (self-system) interact to influence the entire dual-system. The authors propose that the dual-system is dynamic and constantly updated as illnesses change over time; they propose that the system is driven by the integration of information from schematic and propositional memory structures, whereby the former includes concrete sources of information (e.g. somatic experiences) and the latter includes sources of information that derive from semantic concepts, inferences and outcome expectations about illness.

According to Leventhal *et al.*, (1992), representations in the SRM have at least five dimensions, each of which are endorsed at differing levels depending on the illness being explored and each of which determine behavioural strategies for managing illness:

1. Identity: beliefs about the indicators of the illness.
2. Time-line: beliefs about the illness course, e.g. chronic or acute.
3. Consequences: beliefs about the impact of the illness e.g. costs incurred.
4. Antecedent causes: beliefs about triggers for the illness or illness origins.
5. Cure/control: beliefs about the extent to which the illness can be cured or managed.

Research exploring illness representations of prostate cancer derived from dimensions from the SRM has shown a link between the severity of prostate cancer dimensions and emotional wellbeing, whereby more severe consequences were found to be associated with poorer emotional wellbeing (Traeger *et al.*, 2009).

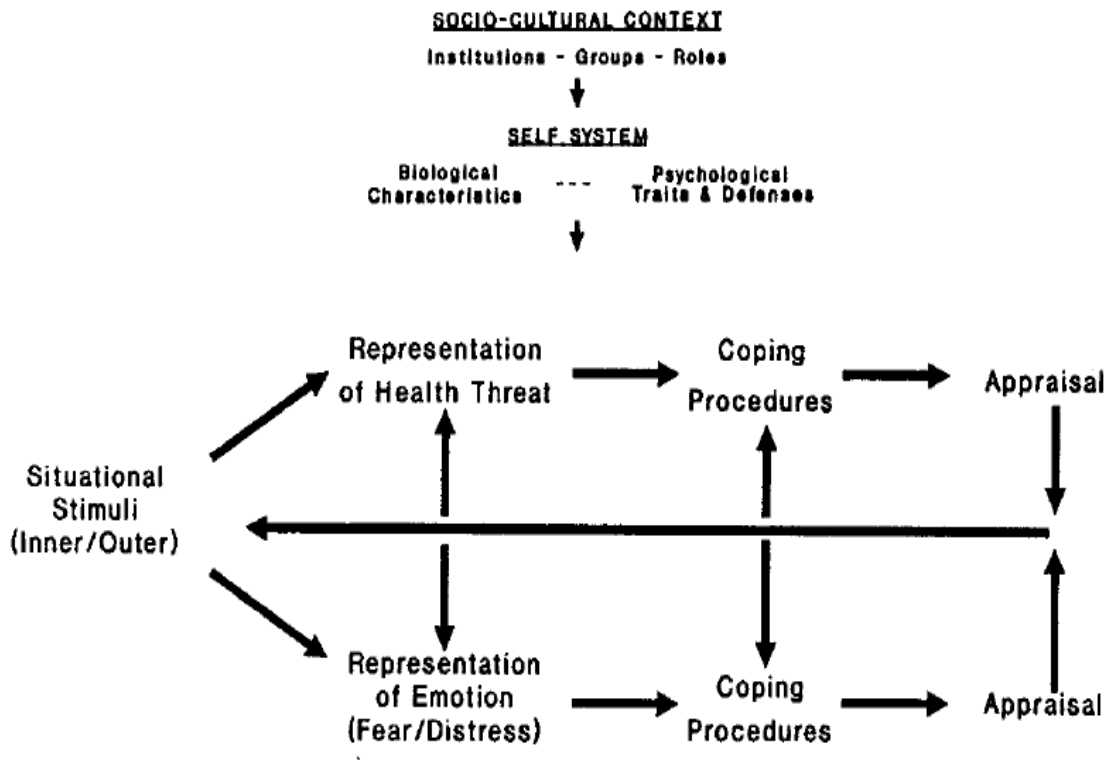


**Figure 1.2: Leventhal, Diefenbach and Leventhal's (1992) Self-Regulation Model**

There is also evidence to suggest that measures of health-related QoL are influenced by certain cognitive representations of prostate cancer. For example Green *et al.* (2002) found that health-related QoL in terms of self-reported existential satisfaction, physical/urinary functions, social/role functions and subjective cognitive function in men with prostate cancer was higher in those men who reported lower threat appraisals. Wallace (2003) also identified a positive relationship between anxieties relating to uncertainty about prostate cancer and perceived illness threat, whereby this also influenced health-related QoL. Similarly, Krongrad *et al.* (1997) found that higher self-efficacy was associated with higher health-related QoL in men with prostate cancer.

The way in which illness representations change over time and influence coping is also significant and is demonstrated in a study by Nanton *et al.* (2009); uncertainty among men with prostate cancer was determined qualitatively in this study at different time-

points during men's cancer journeys and findings revealed that the degree of uncertainty and related anxieties that occur with prostate cancer vary over the course of the disease, are influenced by personal, disease-related and social factors and impact upon adjustment to illness.

Thus, it seems that certain cognitive appraisals, in the form of dimensions of illness perception, may play a role in the degree to which prostate cancer and its associated side-effects are perceived to be problematic and are managed to some extent in this population.

### 1.3.3 Cognitive-behavioural influences on HF/NS

Few studies explore the type of cognitive appraisals and behavioural reactions associated specifically with HF/NS in men (rather than HF/NS as an ancillary problem). Grunfeld *et al.* (2012) are one exception; they qualitatively explored the effects of androgenic hormone treatment, particularly HF/NS, on daily life and coping in men with metastatic prostate cancer; the authors found that HF/NS, along with gynaecomastia, cognitive decline, and changes in sexual function, were the most commonly reported side-effects of treatment and that HF/NS impacted on daily life and sleep, affected mood and resulted in various behavioural responses. Men in this study reported a lack of control over HF/NS; some were unaware of the cause for their symptoms, and cognitions and emotional reactions related to themes of irritation, annoyance and embarrassment, whereby men expressed concern about others' interpretations of their reactions to flushes and a reluctance to disclose their prostate cancer and related symptoms to others due to feelings of embarrassment (Grunfeld *et al.*, 2012). Thus, perceptions about control over HF/NS, the self (in terms of self-efficacy and HF/NS interference) and perceptions about others may be important features in men's cognitive-behavioural experiences of HF/NS.

The majority of the research about HF/NS cognitions and behaviours and the way in which they influence HF/NS focuses on women. Hunter (2003) devised a cognitive-behavioural model of premenstrual problems and menopausal hot flushes that highlights the central role of cognitive appraisals about premenstrual or menopausal

symptoms and the self within a system in which thoughts, feelings and behaviours interact. As the name suggests, the model can be applied to either premenstrual problems or symptoms experienced during the menopause; in this description, application to menopausal symptoms will be used in order to address the relationships associated with appraisals about HF/NS. This model, illustrated in figure 1.3, can be considered alongside Hunter and Mann's (2010) cognitive-behavioural model of HF/NS in that it elaborates the content and form of cognitive representations of HF/NS and the menopause as they appear in Hunter and Mann's (2010) model.

Hunter's (2003) model illustrates the various factors that interact with centralised appraisals about HF/NS and the self. For example, it demonstrates the way that appraisals of HF/NS are influenced by perceptions of somatic changes during HF/NS and by cognitive constructs (cognitive assumptions), which are shaped by beliefs about the self, others and the world, whereby these beliefs are generated from life experiences and socio-cultural values (Hunter, 2003). Some psychosocial factors, including stress, are also illustrated in the model as elements that shape cognitive appraisals as well as influencing somatic changes and interacting with mood. Like, Hunter and Mann's (2010) model, this model shows an interaction between cognitive appraisals, behavioural reactions and mood; it illustrates the way in which mood and behavioural strategies have a two-way interaction with each other but also with appraisals of HF/NS and the self whereby they are both influenced by and are influencing these appraisals.

The interactions depicted in Hunter's (2003) model have important implications for the way in which HF/NS are experienced given that it illustrates the way in which potentially negative appraisals about HF/NS may be generated and maintained. There is evidence to suggest that certain cognitive appraisals about HF/NS are related to more problematic HF/NS; these include negative or catastrophic beliefs and low perceived control (Hunter & Liao, 1995; Reynolds, 1997, 2000; Rendall *et al.*, 2008), whereby negative beliefs included those about the self both socially and in response to HF/NS (i.e. in terms of self-efficacy or perceived ability to cope with HF/NS).

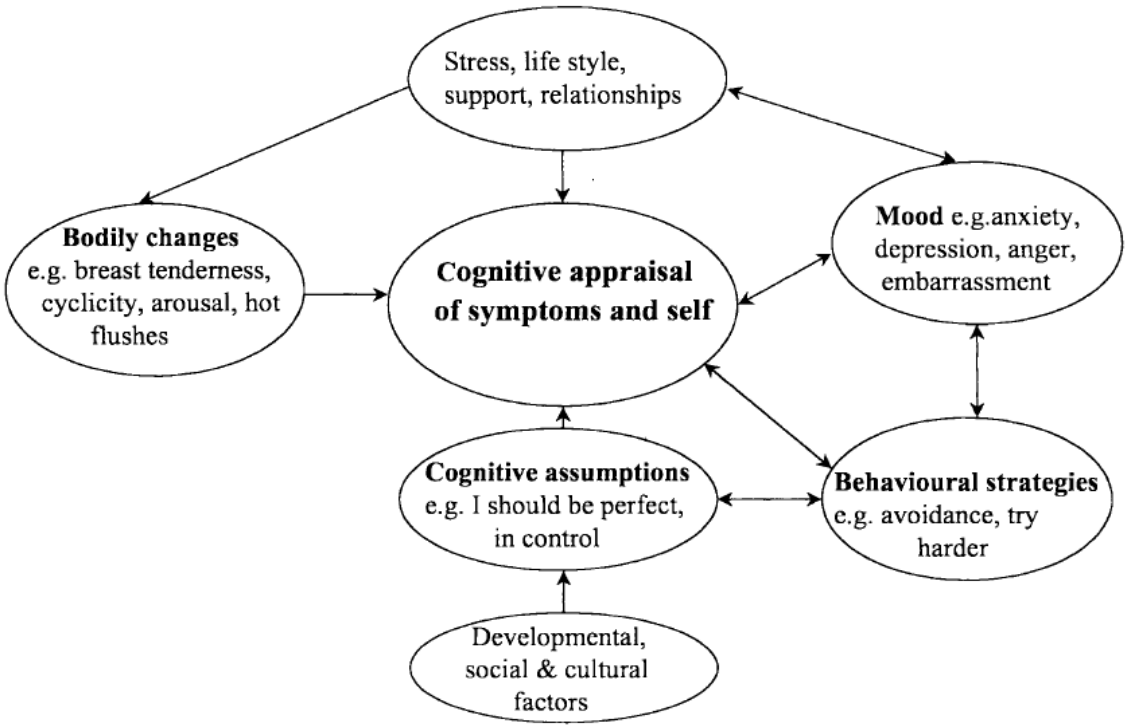


**Figure 1.3: The cognitive-behavioural model of premenstrual problems and menopausal hot flushes (Hunter, 2003)**

Reynolds (1997, 2000), via the administration of questionnaires, found that women reporting high levels of distress caused by HF/NS reported having a greater proportion of highly negative or catastrophic appraisals of hot flush experiences during the hot flush, than women with low distress ratings. Reynolds (2000) also found that the level of perceived control over HF/NS was related to the proportion of catastrophic thoughts, whereby women who reported more catastrophic thoughts had lower levels of perceived control. Thus, more problematic HF/NS appear to be associated with extreme negative and catastrophic thoughts and these in turn are thought to be linked to low perceived control over HF/NS.

Perceived control has also been found to be directly associated with the level of hot flush distress. Hunter and Liao (1995) found that low self-esteem and loss of control beliefs, such as feeling that one has little control over HF/NS, varied between those who regarded flushes as problematic and those who did not, whereby women reporting more problematic HF/NS had lower self-esteem and reported more loss of control beliefs.

Rendall *et al.*, (2008) used factor analysis to develop a 27-item Hot Flush Belief Scale (HFBS). The scale contains items which fall into three thematic categories: beliefs about self in social context, which involves self-reflection on interpersonal embarrassment, beliefs about coping with hot flushes and beliefs about coping with night sweats/sleep, which both involve consideration of self-efficacy. Findings from the study revealed that a higher proportion of negative beliefs across each of the three categories were significantly correlated with higher distress ratings and lower perceptions of coping. Thus, more negative beliefs relating to the social and interpersonal consequences of HF/NS on the self and self-efficacy also seem to be associated with HF/NS that are perceived to be problematic.

Given that more severe or negative illness representations of prostate cancer have been associated with poorer psychosocial outcomes, it is possible that cognitive appraisals specifically about HF/NS in these men may too influence perceptions and experiences of HF/NS.

### 1.3.4 Behavioural reactions to HF/NS

Behavioural reactions specifically related to HF/NS have not been researched comprehensively in either women who experience menopausal HF/NS or men who experience HF/NS as a result of hormone treatment for prostate cancer. There is however, some recent literature investigating the behavioural reactions reported by women who experience HF/NS and some research indicating the types of reactions reported by men.

Hunter, Coventry, Mendes *et al.*, (2009) found that women experiencing moderate to severe menopausal HF/NS after treatment for breast cancer identified several strategies for dealing with HF/NS. Reactions included carrying on and ignoring flushes, taking steps to cool down which included preventative (e.g. wearing easily removable layers or always carrying water) as well as reactive behaviours (e.g. using a fan or wet wipes), avoidance of situations (e.g. social and intimate situations) and communicating with others in particular ways (e.g. using humour or openness) when dealing with a hot flush during social situations. The authors concluded that women displayed a range of

behaviours to manage HF/NS which were consistent with those seen in healthy menopausal women and hypothesised that some of these behaviours may have been more helpful than others. Hunter and Mann (2010) postulate that behaviours such as avoidance of situations act as safety behaviours similar to those seen in panic disorder and social anxiety; such behaviours reduce the opportunity for the development of alternative interpretations about what might happen in the situation to contrast with the catastrophic or negative interpretations that fuel the avoidance. Thus, certain behavioural reactions to HF/NS could contribute to the perception of flushes as problematic via the maintenance of negative beliefs (Hunter & Mann, 2010).

A measure of behavioural reactions to HF/NS in women with the menopause, known as the hot flush behaviour scale (HFBehS), was recently devised by Hunter *et al.*, (2011); the 11-item scale was generated using factor analysis after 140 women aged from 28 to 68 with HF/NS completed an initial questionnaire. The HFBehS includes behavioural reactions that fall into three categories: positive behavioural strategies (e.g. ignoring HF/NS), practical cooling behaviours (e.g. carrying a fan) and avoidance behaviours (e.g. avoiding social situations due to HF/NS). Hunter et al., (2011) found that negative HFBehS scores correlated with negative beliefs about HF/NS and higher problem-ratings of HF/NS, which provides support for the proposed relationship between behavioural reactions and cognitive appraisals as presented in Hunter and Mann's (2010) cognitive model.

A report by Coyne *et al.*, (2006) assessing the incidence of hot flushes among patients with prostate receiving androgen deprivation therapy revealed that the most common reaction by men was to 'do nothing', whereby 96.7% of the men enrolled in the study were not receiving treatment for their hot flushes. Conversely, Grunfeld *et al.*, (2012) found that men engaged in a range of behaviours to manage their HF/NS, including strategies to cool down (e.g. clothing removal, fanning oneself, altering the temperature of the room) and strategies to counteract any sweating that occurred during HF/NS (e.g. towelling oneself and changing wet pillows). However, these behaviours tended to be associated with feelings of embarrassment and this was found to affect disclosure about symptoms to others, including friends and work

colleagues (Grunfeld *et al.*, 2012); the extent to which men reported symptoms to health professionals was not explored as part of this study.

When considering general health-related behaviours, research suggests that men are less willing to seek support than women (Courtenay, 2000a, 2000b; Klem *et al.*, 1999) and when they do, they prefer to share information rather than emotions (Krizek *et al.*, 1999; Kiss & Meryn, 2001).

Thus it seems that there is limited literature on behavioural reactions to HF/NS in men, however existing literature suggests that men may have a range of reactions to HF/NS as do women, but that they may be less likely to seek support for their problems and may have a preference for information-focussed support where they do seek support.

### 1.3.5 Assessment of cognitions and behaviours associated with HF/NS

The most comprehensive measure of the cognitive representations associated with HF/NS is the HFBS devised by Rendall *et al.*, (2008). The HFBS was designed to measure the cognitive appraisals which menopausal women associate with their experiences of HF/NS. It has been used in several studies to assess the cognitive appraisals associated with HF/NS however it does not assess behavioural reactions to HF/NS. The HFBehS (Hunter *et al.*, 2011) has since been developed to identify the behavioural reactions associated with HF/NS in women; it is the first measure of HF/NS behaviours used by women, has been found to be psychometrically sound (Hunter *et al.*, 2011) and has been used in randomised control trials assessing cognitive-behavioural interventions for HF/NS in women (Ayers *et al.*, 2012; Mann *et al.*, 2012).

The applicability of the HFBS and the HFBehS to men who experience HF/NS is as yet unknown. There are presently no measures to assess properties such as HF/NS cognitions and behaviours in men who experience HF/NS as a result of hormone treatment for prostate cancer.

More general measures of HF/NS include psychosocial measures such as the Hot Flash Related Daily Interference Scale (Carpenter, 2001) and subjective measures of frequency, severity and problem-ratings via the use of diaries (Hunter, Coventry,

Mendes *et al.*, 2009) and/or the Hot Flush Rating Scale (HFRS, Hunter & Liao, 1995). Subjective measures can be supplemented or replaced by objective measures such as sternal skin conductance monitors. Such objective measures are thought to be reliable indicators of hot flush incidence (Cohen *et al.*, 2005), however the validity of such measures have been called into question (Carpenter *et al.*, 2005).

The Menopause Representations Questionnaire (MRQ) was devised by Hunter and O'Dea (2001) and consists of 37-items assessing women's cognitive representations of the menopause with regard to identity, consequences, time-line and control and/or cure. This is an assessment of illness perception which focuses on the meanings and appraisals relating to the cause of HF/NS in women. Such cognitions have been associated with specific beliefs about HF/NS, for example Rendall *et al.* (2008) found that those women with more negative beliefs about HF/NS were more likely to have lower perceived control over their symptoms as measured by the MRQ; they were significantly more likely to attribute their symptoms to the menopause and to hold beliefs that the menopause had negative consequences on their life.

The MRQ cannot be applied to men with prostate cancer however, another measure of illness perceptions which could serve to elicit more general meanings and appraisals, possibly relating to prostate cancer and hormone treatments, is the Brief Illness Perception Questionnaire (B-IPQ, Broadbent *et al.*, 2006). This is a 10-item scale which draws on Leventhal *et al.*'s (1992) SRM to provide a rapid assessment of the cognitive and emotional representations of illness. Each item of the scale represents a dimension of illness perception: consequence, timeline, personal control, treatment control, identity, concern, coherence, emotional representation and causality.

### 1.3.6 Cognitive-behavioural interventions for hot flushes

The cognitive model of menopausal HF/NS proposed by Hunter and Mann (2010) identifies specific target areas for intervention, whereby cognitive-behavioural treatment has been specified as a possible method for monitoring and altering the precipitating and perpetuating elements of HF/NS at each of the four levels of the

model: information input, symptom perception, cognitive appraisal and behavioural reactions.

Treatment components of this CBT approach include the identification and modification of triggers, paced breathing, attentional focus, distraction, stress management, cognitive therapy and psycho-education to target the physiological aspects of HF/NS and the processes that can result in the increased detection of them (Hunter & Mann, 2010). Similar approaches are thought to be useful at the cognitive appraisal level whereby mindfulness approaches are additional and thought to improve acceptance of flushes and perceived self-efficacy when coping with them. Interventions targeting behavioural reactions include behaviour experiments in order to reduce of social avoidance and encourage more helpful reactions, and CBT for insomnia (Hunter & Mann, 2010).

There is evidence to suggest that the cognitive-behavioural strategies outlined by Hunter and Mann (2010) can be effective. For example, Hunter and Liao (1996), in an initial exploratory study, compared the effectiveness of CBT in the treatment of HF/NS with that of hormone replacement therapy (HRT) in healthy menopausal women using a patient preference design; both treatment groups were compared with a no treatment control group whereby women were monitored. CBT treatment components included psycho-education, stress management, relaxation and management of precipitants to hot flushes and four therapy sessions were provided. Findings revealed that CBT and HRT were both effective compared with controls, whereby both resulted in a 50% reduction in the frequency of hot flushes. However, CBT alone resulted in reductions in anxiety and depression scores. Similar findings reporting the effectiveness of treatments for HF/NS, in terms of reductions in HF/NS frequency and/or problem ratings, have been reported for standalone applied relaxation in a small sample of menopausal women (Wijma *et al.*, 1997) and for group CBT treatment in small samples of women with breast cancer (Hunter, Coventry, Hamed *et al.*, 2009) and healthy women (Keefer & Blanchard, 2005). Improvements in other aspects of psychosocial functioning intervention have also been reported in some of these small-scale studies; for example, improvements in mood, sleep and QoL

(Hunter, Coventry, Hamed *et al.*, 2009) and improvements in psychological wellbeing (Wijma *et al.*, 1997).

The effectiveness of psychoeducational interventions, which included relaxation, paced breathing and cognitive-behavioural strategies, in the management of HF/NS was evaluated in a meta-analysis (Tremblay *et al.*, 2008); the authors concluded that although these interventions seem to result in improvements in HF/NS frequency in women, the quality of the studies investigated was questionable, whereby many studies included small sample sizes. Two randomised controlled trials have recently been conducted, assessing cognitive-behavioural interventions in larger samples of healthy women (Ayers *et al.*, 2012) and women who experience menopause following treatment for breast cancer (Mann *et al.*, 2012). The effectiveness of 4-week interventions involving either group CBT or guided self-help CBT were assessed in 140 healthy menopausal women and, compared to a no treatment control group, problem-ratings of HF/NS were found to reduce significantly and improvements in mood and QoL were reported for both intervention groups 6 weeks after randomisation (Ayers *et al.*, 2012). Similarly, the effectiveness of weekly group CBT for HF/NS over 6 weeks was demonstrated in 96 women with breast cancer; group CBT plus treatment as usual was compared to a group receiving treatment as usual alone and findings 9 weeks after randomisation revealed that group CBT was more effective at reducing problem ratings of HF/NS than treatment as usual alone and gains were maintained up to 26 weeks following intervention (Mann *et al.*, 2012).

Thus, it seems that cognitive-behavioural techniques may effectively lead to a positive change in the experiences of HF/NS, whereby they have been shown to reduce problem-ratings of HF/NS and promote improvements in aspects of psycho-social functioning.

### *1.4 The socio-cultural meanings of hot flushes*

Hunter and Mann's (2010) cognitive model and Hunter's (2003) cognitive-behavioural model of menopausal hot flushes both demonstrate the significant role that cognitive appraisals play in relation to HF/NS and the impact they can have on the perception of

HF/NS and subsequent behavioural reactions. Leventhal *et al.*'s (1992) SRM also highlights the way that objective and emotional representations of illness can influence coping and appraisals about illness management. The role of socio-cultural context is not explicitly identified in Hunter and Mann's (2010) model, however both the SRM (Leventhal *et al.*, 1992) and the cognitive-behavioural model of menopausal hot flushes (Hunter, 2003) acknowledge the influence of this factor on the development of an individual's representations and appraisals. Thus socio-cultural attitudes and beliefs originating from an individual's socio-economic and ethnic background could play a role in exacerbating or ameliorating the experience of HF/NS; such beliefs may influence an individual's perception and subjective reporting of symptoms as well as affecting their appraisals about the extent to which symptoms are problematic, their behavioural reactions and their judgements about HF/NS following these behavioural reactions.

### 1.4.1 Discourses about hot flushes in women

There are cultural differences in women's experiences of HF/NS; women in western cultures such as Europe and North America have been found to report experiencing these symptoms more so than women from non-western cultures such as India, Indonesia, Taiwan, Hong Kong, Japan, Singapore, China, Korea, Thailand, and Malaysia (Lock, 2005). For example, Gupta *et al.* (2006) compared the experiences of HF/NS in a migrated Asian population from the Indian subcontinent living in Birmingham in the UK with the experiences of a matched sample of Caucasian women living in the same area and also with a sample of Asian women with similar socioeconomic backgrounds living in Delhi, India. They found that women living in Delhi reported significantly fewer HF/NS than the two groups of women living in Birmingham. Cultural factors such as religion, diet, lifestyle, reproductive practices, climate, the attribution of symptoms and the cultural meanings of the menopause and ageing have been implicated as possible explanations for such differences in reported experiences of menopausal HF/NS (Melby *et al.*, 2005; Hunter & Rendall, 2007; Hunter, Gupta *et al.*, 2009).

HF/NS occur due to menopause, thus the cultural meanings associated with menopause are likely to influence appraisals associated with these symptoms. According to Hunter's (2003) model of menopausal hot flushes, cognitive appraisals about menopausal symptoms are influenced by cognitive assumptions about the self, others and the world, which develop over time and are moulded by developmental, social and cultural factors. Thus, if societal views of the menopause are negative then cognitive assumptions about the menopause in the self, others and the world may be negative, resulting in less favourable appraisals about HF/NS and the self.

As described previously, research suggests that some women experience catastrophic thoughts and negative self-appraisals in relation to their hot flushes (Reynolds, 1997; 2000) particularly in the three domains identified by Rendall *et al.*, (2008): beliefs about self in social context, about coping with hot flushes and about coping with night sweats and / or sleep. The themes of shame and stigma were apparent in the domain relating to social situations and issues relating to self-efficacy were apparent in the domains relating to coping ability (Rendall *et al.*, 2008). These experiences are similar to those reported by women who have experienced menopausal symptoms following breast cancer treatment (Hunter, Coventry, Hamed *et al.*, 2009). The majority of the women in these studies were from a western background (British) and there is evidence to suggest that the menopause is associated with negative discourses in the western world, such as being seen as a time of poor emotional and physical health (Hunter & Rendall, 2007) or a time of loss of reproductive ability, which could be linked with ageist and sexist attitudes or social positions (Hope *et al.*, 1998; Fu *et al.*, 2003). This is in stark contrast to some views held by women from non-western cultures such as North Indian women in a study by Flint and Smail (1990) who viewed menopause as a positive life change and women in Asian cultures who view menopause as associated with increased power and respectability (Sommer *et al.*, 1999). Such positive views could be associated problem-free or the reduced reporting of menopausal symptoms in comparison to women from western cultures.

Thus, socio-cultural attitudes towards HF/NS, by way of their perceived cause, may influence appraisals about these physiological events and subsequent cognitive-behavioural interactions, including the perceptions and reporting of HF/NS.

### 1.4.2 Discourses about hot flushes in men

Hot flushes and night sweats have been found to occur in healthy men as well as those with prostate cancer and are linked to the natural decline in androgens that occurs with age, a debated male climacteric or andropause that is similar to the menopause in women (Spetz, Fredriksson *et al.*, 2003). Flushing has also been found to occur in men with testicular problems (Norcross & Schmidt, 1986; Feldman *et al.*, 1976) and is a reaction that defines emotional flushing or blushing experienced by most people (Moyhi *et al.*, 1997). Despite the various ways in which HF/NS occur in men, studies exploring individual experiences of HF/NS in this population are lacking; much of the research focuses on measuring the frequency of HF/NS occurrences and, in the case of men with prostate cancer, the extent to which general treatment side-effects impact upon QoL. Thus, socio-cultural attitudes towards HF/NS experiences remain largely unexplored in this population, as do any cultural differences in attitudes.

Although specific socio-cultural attitudes towards HF/NS in men have not been identified, socio-cultural attitudes towards the cause for HF/NS and the implications of having these symptoms may play a role in influencing appraisals and illness representations. Similar influences were found to be significant in the discourses described for women, whereby socio-cultural meanings associated with the menopause (the cause of flushes in women) were found to influence the way in which HF/NS were appraised. Thus, in men with prostate cancer, the discourses associated with hormone treatment and prostate cancer itself may play an important part in the construction of appraisals about HF/NS.

*Prostate cancer and masculinity*

Qualitative explorations of the experiences of prostate cancer and hormone treatment do exist in the literature and according to social-constructionist views of illness, certain illnesses are associated with certain social or cultural meanings (Conrad & Barker, 2010); prostate cancer, due to the nature of its treatment, seems to be associated with a threat to male identity and the psychosocial impact of the treatment for the disease on masculinity is a common theme in qualitative studies in men with the disease. For

example, Chapple & Ziebland (2002) interviewed 52 men, the majority of whom were middle class and white British, about their experiences of prostate cancer. They found that men reported a reduction in their sense of masculinity due to the side effects of hormone treatments which affected libido, energy, ability to work, body shape, bodily secretions (hot flushes and sweating), enthusiasm, the sense of control and competitiveness. This belief about a loss of male identity was thought to be linked to the men's shared understanding of the impact of the alteration of the balance of male hormones on functions that were thought of to be associated with the male identity (e.g. sexual function) and possibly an awareness of their bodies being affected by female hormones (Chapple & Ziebland, 2002). These findings are similar to studies investigating health-related QoL in men with prostate cancer who are undergoing hormone treatment, which have found that hormone treatments are more frequently associated with reduced sexual, social and role functioning (Green *et al.*, 2002). There is also some qualitative research exploring the cognitive strategies that men with prostate cancer adopt in order to cope with perceived feminisation due to bodily changes and other side-effects of hormone treatment (Navon & Morag, 2003) and the ways in which men positively utilise, reject and/or reframe traditional ideas of masculinity in order to cope with bodily changes that affect their sense of masculinity (Oliffe, 2006).

*Prostate cancer and the visibility of illness*

Prostate cancer and the side-effects of hormone treatment could also be linked to attitudes towards illness and the visibility of illness. General ill health and disability has been found to be associated with powerlessness, whereby this consists of worthlessness in terms of one's ability to meet societal demands, emotional suffering arising from self-dissatisfaction and a sense imprisonment within one's own life due to limited abilities (Strandmark, 2004). These constructs are associated with feelings of shame and can contribute to perceptions of stigma (Strandmark, 2004), thus to be perceived as unwell could be a negative and undesirable experience and any indicators or visible signs of illness such as treatment side-effects, may be associated with negative self-beliefs and the potential for stigma or negative societal attitudes. Perceptions of ill-health have also been associated with threats to masculinity,

particularly in research exploring delayed help-seeking and health behaviours in men (Courtenay, 2000a; Möller-Leimkühler, 2002; O'Brien *et al.*, 2005; Oliffe, 2009).

*Summary*

Thus, it seems that prostate cancer and associated hormone treatment may influence beliefs related to male identity and masculinity as well as self-perceptions in relation to illness. Given that HF/NS are a side-effect of hormone treatment it is likely that appraisals about these side-effects tap into such discourses. However, it is of note that it may be difficult to disentangle the experiences of HF/NS from the experiences of prostate cancer and its treatment; Owens *et al.*, (2003) attempted to explore the experiences of men with prostate cancer who were undergoing radiotherapy and found that the treatment contributed to only part of men's experiences; the authors noted the importance of each man's individual experience of prostate cancer and treatment and their previous experiences. They report the difficulties of attempting to isolate a single component of the cancer experience.

### 1.4.3 Socio-cultural differences in men with prostate cancer: impact on HF/NS appraisals and behavioural reactions

The discourses that were associated with prostate cancer and hormone treatment, above, were identified in samples from certain socio-cultural groups (e.g. discourses relating to masculinity were identified in white, middle class men) and may therefore reflect specific socio-cultural attitudes which may or may not differ from the attitudes of individuals from other socio-cultural groups. In the study by Chapple and Ziebland (2002), the authors noted that those constructs associated with masculinity in white men may be different in black men and men from other ethnic backgrounds, as well as those from different socio-economic groups. For example, masculinity in white, middle class men has been found to be associated with economic, social and political power (Kaufman, 1999) and physical freedom (Connell, 1995), whereas in other cultures this

construct has been associated with sexual prowess (Cheng, 1999) and may go beyond uni-dimensional, traditional ideas of manhood and masculinity (Hunter & Davis, 1994).

There are a number of significant cultural differences that exist in men with prostate cancer, which relate to incidence of the disease and disease knowledge. For example there is evidence to suggest that there is a higher incidence of prostate cancer in men from Afro-Caribbean descent (Sakr *et al.*, 1996; Greenlee *et al.*, 2000; Jack *et al.*, 2007; Ben-Shlomo *et al.*, 2008) but that within this population there is a lower level of knowledge and awareness of prostate cancer compared to Caucasian men (Boyd *et al.*, 2001; Agho & Lewis, 2001; Rajbabu *et al.*, 2007). Attitudes towards the control and treatment of prostate cancer have been found to be more negative in black British men compared to white British men (Rajbabu *et al.*, 2007) and knowledge relating to personal risk of prostate cancer has been found to be particularly lower in black men than in white men (Jones *et al.*, 2005; Rajbabu *et al.*, 2007), whereby black men have been found to have lower symptom knowledge and awareness of the increased risk of developing the disease (Rajbabu *et al.*, 2007). According to illness representation models, such as Leventhal *et al.*'s (1992) SRM, appraisals about perceived risk (illness threat appraisals) that are particularly based on interpretations of ongoing illness indicators influence coping strategies; thus, men who have low threat appraisals of illness, which may relate to the extent of their knowledge of their illness and their attributions of symptoms, may be less likely to engage in positive health behaviours, such as help-seeking. Cultural differences in disease knowledge may therefore be significant if they affect interpretations of symptoms, perceptions of risk and subsequent behavioural reactions as this would suggest an influence of cultural differences on behaviour and coping. If these appraisals tap into appraisals of HF/NS, then the way in which HF/NS are managed across cultures in men could be different.

A recent publication by Nanton and Dale (2011) provides the first qualitative exploration of the experiences of treatment and care in solely Afro-Caribbean men with prostate cancer. The authors concluded that the men in their study reported experiences that were influenced by issues related to migration, historical context and culture, whereby the study focussed on men's journey through the prostate cancer pathway and difficulties related to healthcare professional-patient communication.

Thus perceptions of the impact of prostate cancer and hormone treatments may vary across socio-cultural groups; this may also affect associated appraisals relating to HF/NS.

## *1.5 Rationale for this study*

### 1.5.1 Summary of literature

Men with prostate cancer are treated with androgenic hormone therapies that aim to prevent the spread of cancer. These men can experience HF/NS as a result of a thermoregulatory instability which is thought to be triggered by androgenic treatments. Clinical guidance exists for the treatment of HF/NS, whereby the focus is on pharmacological management.

There is evidence that psychological processes, such as cognitions and behaviours, may be involved in the maintenance of HF/NS; measures of these processes have been devised and psychological interventions to tackle maintaining process have been developed. However, these measures and interventions have been developed solely for women who experience these symptoms due to the menopause, thus their applicability to men is unknown.

Research exploring the experiences of HF/NS in women preceded the development of measures of and cognitive-behavioural interventions for HF/NS and provided a guiding framework for their development. There is currently little research considering the experiences of men with cancer who also endure such symptoms. Concepts that draw from cognitive-behavioural models exploring HF/NS in women may be applicable to men if appropriately adapted. Similarly, illness representation models, which are applicable to both men and women and have been explored in prostate cancer, may help to identify cognitive-behavioural associations in men with prostate cancer that may maintain cognitions and behaviours associated with the disease and its treatment side-effects, which include HF/NS. Certain socio-cultural attitudes and beliefs may also play a role in influencing cognitions and behaviours associated with HF/NS; for example the role of perceptions relating to masculinity and visible signs of illness.

There may also be differences in socio-cultural attitudes and beliefs (whereby socio-cultural is defined as a combination of influences on an individual's background and upbringing such as socio-economic status and ethnicity), that are specific to certain socio-cultural groups, whereby differences have been identified in white and black men with prostate cancer which could potentially influence cognitive-behavioural reactions to prostate cancer and treatment side-effects, such as HF/NS.

### 1.5.2 Research aims/objectives

This study will attempt to explore the experiences of HF/NS reported by a small sample of men who are experiencing these symptoms as a side-effect of treatment for prostate cancer. Specifically, the cognitive-behavioural components of men's experiences will be explored and they will be considered in relation to existing models of HF/NS experiences.

The experiences of men from two ethnic groups (white and black British/Irish men) will be considered via separate analyses to allow room to explore any socio-cultural differences in experiences and ensure that a wide-range of experiences is explored.

An index of cognitive-behavioural items will be generated from men's experiences, which could be used to develop measures of HF/NS experiences in men with prostate cancer and to inform cognitive-behavioural interventions in this population. No interventions or comprehensive measures of the cognitions and behaviours relating to HF/NS exist for men with prostate cancer, thus this explorative study could pave the way for further research in this domain.

### 1.5.3 Research questions

This study has three main research questions:

1. What are the cognitive appraisals and behavioural reactions associated with HF/NS in men who are receiving hormone treatment for prostate cancer?

2. What types of appraisals and behavioural reactions are associated with flushes that are subjectively rated as more or less problematic and are associated with more threatening illness representations?

3. Are appraisals and behaviours subject to socio-cultural differences, whereby socio-cultural difference refers to any socio-economic and ethnicity-related difference?

# Chapter 2: METHODOLOGY

## *2.1 Study design*

This study follows a mixed-methods design, which is predominantly qualitative but also includes some quantitative measures.

### 2.1.1 Rationale for a qualitative methodology

Qualitative methods were used to explore and analyse the experiences of HF/NS in a small sample of men with prostate cancer (N=19). Given that the experiences of HF/NS in this population are understudied, it was felt that an explorative qualitative method was necessary in order to capture a detailed and varied account of men's experiences. In-depth, semi-structured interviews were used as this allowed certain themes, such as cognitive and behavioural reactions to HF/NS, to be explored while simultaneously allowing participants to elaborate on these themes and introduce items that had not been considered by researchers and clinicians. A similar method was used in a female population by Rendall *et al.* (2008) in the first phase of their study when they were attempting to generate experiences for the development the HFBS. In addition to this, qualitative approaches are thought to be well-suited to studies that focus on process and unique variation, meaning, ethical and interpersonal issues, culture and context (Yardley, 2000); this is because, rather than generating statistical representations of phenomena as is common in quantitative approaches, qualitative approaches involve attempts to understand and interpret social phenomena (Pope & Mays, 2007) and can be carefully designed and analysed to capture individuals' views, meanings, behaviours, interactions and experiences (Pope *et al.*, 2000). Such an approach can strengthen understanding of health and illness (Yardley, 2000) and is used increasingly in health psychology (Pope & Mays, 2007; Yardley, 2000). According to Pope and Mays (1995), qualitative research is essential in the domain of health research because it allows exploration of areas that are less accessible to quantitative methods and it is a

prerequisite for good subsequent quantitative research, particularly in under-researched areas.

### 2.1.2 Rationale for the addition of quantitative measures

Quantitative measures (the HFRS and the B-IPQ) were used to gather subjective information about how problematic HF/NS were and about cognitive representations of prostate cancer respectively; this information was used to establish the extent to which coded themes generated from qualitative analysis interacted with perceptions of problem-ratings for HF/NS and dimensions of illness. These quantitative methods were necessary in order to answer the second study research question. As reported by Bryman and Burgess (1994) quantitative and qualitative methods can be linked to allow the former to map out general patterns in the data and the latter to reveal the processes and nature of the social phenomena involved; in this study, it was hoped that quantitative measures could indicate a general pattern in the reported experiences of HF/NS and prostate cancer representations and that qualitative measures could be used to explore these experiences in greater depth.

## *2.2 Participants and recruitment*

This study began with a purposeful sample recruited from various services within Guy's Hospital (Guy's and St Thomas' NHS Foundation Trust); male participants were recruited from prostate cancer clinics, a prostate cancer support group (PCSG) and a pilot 'Surviving Cancer, Living Life' service for individuals with cancer, their families and carers. All of these services were available to men from London and the south-east of England and the pilot service was available to individuals from anywhere in the UK who had received any part of their cancer treatment within Guys and St Thomas' NHS Foundation Trust. The study sampling frame therefore covered a large region, which was both culturally and socially diverse.

Participants were recruited from the aforementioned sources via a poster which was placed in clinics and contained the primary researcher's contact details (appendix B). Recruitment also took place via recommendations from clinicians, including prostate cancer nurse specialists, cancer care managers, psychologists and urologists at Guy's Hospital. These clinicians identified and contacted potential participants about this study and were provided with study information sheets (appendix C) and both full-sized (A4) and leaflet-sized (A5) versions of the recruitment poster to disseminate to any potential participants. All participants were offered reimbursement for travel costs if they chose to participate in the study.

**Inclusion:**

- Male participants aged 18 and above.
- Participants subjectively report current experiences of HF/NS, at least one per week, of any severity.
- White or black British/Irish men.
- Participants must be able to speak, read and write in English.
- Participants have received hormone treatment (either currently or retrospectively) for prostate cancer (anti-androgen or androgen withdrawal), including participants who may be receiving medical treatment specifically for HF/NS.
- Participants' prostate cancer may be at any stage: localised, locally advanced or metastatic.

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**Exclusion:**

- Individuals with prostate cancer who do not have current experiences of HF/NS or who have never experienced HF/NS.
- Individuals who report experiencing HF/NS but have never received hormone treatment.
- Individuals with Axis I or II DSM-IV TR diagnoses that may impede their ability to participate in the study.

**Table 2.1: Inclusion/exclusion criteria for participant recruitment**

A comprehensive list of the inclusion and exclusion criteria for this study are outlined in table 2.1; maximum variation sampling, including demographic and phenomenal variation (Patton, 2002; Sandelowski, 1995), was used whereby men were recruited if they were from one of two ethnic groups, had received hormone treatments for prostate cancer and subjectively reported experiencing HF/NS, of any severity, as a

result of their hormone treatment. Broad inclusion criteria relating to prostate cancer stage and the severity of HF/NS were applied to ensure that men with a range of experiences were included in the study. An ability to speak, read and write in English was essential due to the heavy load on English-language tools within this study and also due to the limited funding available, which meant that the employment of translation services was not possible.

The recruitment sample for this study was not fixed but was dependent on the point at which thematic saturation was reached. It was estimated that an approximate sample of 20-30 men would likely be sufficient for separately exploring men's experiences of HF/NS among men from both ethnicities. This was based on Morse (1994)'s recommendation that qualitative explorations of experiences require a minimum of 6 participants and based on Sandelowski's (1995) suggestion that phenomenological studies which aim to generate items for an instrument should include approximately 25 descriptions of an experience.

### *2.3 Procedure*

#### 2.3.1 Opting in and screening

Potential participants opted into the study in one of three ways: (a) by initiating phone or email contact with the primary researcher via clinic posters and leaflets; (b) by verbally consenting to either meeting the primary researcher within clinic or being contacted by this researcher by phone or (c) by approaching the primary researcher within the PCSG. All those who opted into the study were screened either by phone or face-to-face using a checklist that summarised inclusion and exclusion criteria (appendix D); they were also asked to provide socio-demographic information.

Following screening, eligible participants who were interested in study participation were sent a participant information sheet and consent form (appendix C) outlining the study aims, risks, benefits, confidentiality issues, plans for data use, study withdrawal procedures and the contact details of researchers (with information about what to do to receive a summary of study findings). They were also sent an appointment letter for

an in-depth interview with the primary researcher (appendix E), along with a socio-demographic questionnaire, a HFRS, a B-IPQ (appendices F-H) and a map with directions to one of two possible interview locations; the interview site was determined by participants following successful screening. Participants were asked to bring all documents, including the consent form, with them to interviews.

### 2.3.2 Interviews

In-depth, semi-structured interviews, lasting 45-75 minutes, took place with each participant in one of two locations (Guy's Hospital or the Institute of Psychiatry). Interviews followed a schedule (appendix I) which was adapted from Rendall *et al.* (2008). Each interview consisted of three stages, described below:

- *Preliminary stage*: this was an introductory stage in which participants were reminded of study aims and their right to withdraw and were given an opportunity to ask any questions. Participants were also paid and given a receipt for payment at this point and the consent form was reviewed and signed.
- *Interview stage*: this included the main body of the interview whereby participants were asked open-ended questions as appear in the schedule and a Padesky (1994) sentence completion task was administered in order to elicit the cognitive triad (one's view of the self, others and the world) in relation to HF/NS. The sequence of items presented varied with each participant depending on the course of discussions during interviews.
- *Concluding stage*: this included concluding statements about the interview and participants were given the option to obtain study results once they were finalised. Participants were given an opportunity to express their views about the interview, such as whether or not it fully captured their experiences, and they were also invited to add any information to the interview that they felt may have been overlooked.

All open-ended interview questions framed the topics that were discussed around a flexible structure that was responsive to any emergent issues that were relevant and important to the participant. Questions were generated from interview items used by

Rendall *et al.* (2008) as well as from the HFBS, the HFBehS and literature on cognitive-behavioural reactions to HF/NS in men and women. In the in-depth interviews reported by Rendall *et al*. (2008), two interviews took place with each participant in order to validate participants responses and to elaborate on items generated in the initial interview; modified thought records were also completed by participants in the period between the first and second interview to aid recall of flush-related cognitions occurring in different contexts. Four participants were interviewed in that study. Due to the larger sample size in this study and time constraints, two interviews were not possible for each participant, however interview items allowed for the identification of flush-related cognitions that occurred in different contexts, for example, one item asked participants to recall a recent experience of a hot flush with probes exploring the situational context, mood, actions taken, thoughts or images, the intensity of the flush before and after the first action taken and interpretations of the flush.

The administration of the interview schedule was reviewed by both research supervisors via consideration of transcripts after two interviews to ensure that the information being collected was coherent and relevant; adjustments to the schedule were made following these reviews; further adjustments were made by the primary researcher following subsequent interviews, whereby questions were introduced or removed based on emergent themes.

All interviews were audio-recorded and transcribed in verbatim. All recordings and transcribed documents were labelled and coded to maintain anonymity.

### *2.4 Qualitative Analysis: Generation of a cognitive-behavioural index*

All transcripts were managed using Nvivo (version 9.2.70.0 produced by QSR International), a computer-assisted qualitative data analysis software programme. The framework approach (Ritchie & Spencer, 1994; Pope *et al.*, 2000) was selected as the method for qualitative analysis.

### 2.4.1 Rationale for adopting the framework approach

This study had specific research questions and specific areas of interest, that is, the exploration of HF/NS experiences among men with prostate cancer with the aims of identifying and exploring the cognitions and behaviours associated with HF/NS and exploring any cognitive-behavioural differences among men with differing characteristics. Thus, qualitative exploration was a study aim but the process began with a deductive stance; this is uncommon in most qualitative research but not uncommon in qualitative methods used in applied research. It was therefore felt that an analytical approach appropriate for analysing qualitative research with such deductive elements was required and the framework method fulfils this criterion (Pope *et al.*, 2000). Framework analysis was originally developed for applied or policy research (Pope *et al.*, 2000) however its general principles have been successfully applied to a wide range of studies (Ritchie & Spencer, 1994). The key characteristics of the approach are outlined in figure 2.1.

*Grounded or generative:* it is heavily based in, and driven by, the original accounts and observations of the people it is about.

*Dynamic:* it is open to change, addition and amendment throughout the analytic process.

Systematic: it allows methodical treatment of all similar units of analysis.

Comprehensive: it allows full, and not partial or selective, review of the material collected.

*Enables easy* retrieval: it allows access to, and retrieval of, the original textual material.

*Allows between- and within-case analysis:* it enables comparisons between, and associations within, cases to be made.

*Accessibility to others:* the analytic process, and interpretations derived from it, can be viewed and judged by people other than the primary analyst.

**Figure 2.1: 'Key features of "framework"' (Ritchie & Spencer, 1994, p. 176)**

Given the specificity and deductive nature of the research questions in this study, it was felt that inductive qualitative approaches, such as grounded theory (Glaser, 1992; Strauss & Corbin, 1998), were not appropriate; it was not the aim of this study to

generate theory from experiences but instead to explore and report particular aspects of experiences. In addition to this the analytic methods and goals of other qualitative approaches, such as discourse analysis and narrative analysis were considered, however discourse analysis focuses on language and the process by which experiences are communicated (Starks & Brown Trinidad, 2007) and narrative analysis focuses on exploring chronology and re-telling stories of experiences (Creswell, 2007); these were not the aims of this study. Interpretative phenomenological analysis (Smith & Osborn, 2008) and thematic analysis (see Braun & Clarke, 2006) were two possible methods that met the aims of this study in that both methods focus on exploring and categorising phenomena while retaining the integrity of the original data. The framework method was adopted instead of these approaches due to the quality of the analytical process and the comparative functions that can be performed within the approach via the use of charts; framework analysis provides coherence and structure to vast amounts of qualitative data and comparisons can be made within- and between-cases, whereby in all circumstances the research process and methodology undertaken during qualitative analysis is accessible and explicit (Ritchie & Spencer, 1994).

### 2.4.2 Systematic analysis using the framework method

The framework method is the system by which qualitative source material is subject to five interconnected, analytical processes before it is ultimately organised into superordinate units that represent the dominant themes within the source material. The processes or stages used to analyse source material are as follows:

- Familiarisation
- Identifying a thematic framework
- Indexing
- Charting
- Mapping and interpretation

Each process, and the way in which it was applied to analysis in this study are described in appendix A; it important to note that the order in which each process is

presented is simply to establish a logical understanding of the way in which the processes are linked. During analysis for this study identifying a thematic framework occurred throughout the analytic process and this process along with familiarisation, indexing and charting all influenced one another other throughout the process; thus none of these processes are mutually exclusive.

The process of analysis determined the number of participants who were interviewed; once novel themes were no longer apparent and the thematic framework was established, data saturation was assumed and the need to interview further participants was reviewed.

### *2.5 Additional and quantitative measures*

Demographic information was collected from all participants using a socio-demographic questionnaire; this included information such as age, living status, sexuality, religion, highest level of education, employment status, ethnic origin and clinical stage of prostate cancer (appendix F). In addition to this, the HFRS was provided in order to gather information about frequency and problem-ratings of HF/NS (appendix G) and the B-IPQ was provided in order to gather information relating to illness representations about prostate cancer and hormone treatment (see appendix H). Descriptive statistical analyses of these measures were performed using IBM's Statistical Package for the Social Sciences (SPSS) Statistics version 17.

*HFRS: This contains 2 items assessing HF/NS frequency and 3 items assessing the extent to which HF/NS are problematic, cause interference and are distressing. An average of the latter items can be calculated to generate an overall HF/NS problem-rating score.*

*B-IPQ: This measure contains 8 items each representing one dimension of illness. Dimensions include consequence, timeline, personal control, treatment control, identity, concern, coherence and emotional representation. Items are rated on a 10-*

*point scale and can be combined to calculate an overall illness threat score between 0 and 80; higher scores represent greater illness threat.*

### *2.6 Reliability and Validity*

The rigour of the qualitative analyses undertaken in this study was monitored by two reviewers and one research supervisor. Indexed codes within a subsample of transcripts were scrutinised by two reviewers, who considered the extent to which codes were reflective of the units of data that they represented. Inter-coder agreement or interpretive convergence (Saldaña, 2009) was not calculated, however group discussions took place in which any discrepancies in the reflectiveness of codes were addressed and mutually agreeable codes were established. For example, some codes were seen to reflect similar constructs and combined and others were renamed to better reflect their content. Such group discussions involved both reviewers and the primary researcher. One research supervisor was involved in early stages of the framework method, whereby the indexing and early stages of charting of source data was reviewed during discussions in monthly meetings and corresponding research memos were produced to aid analysis.

Qualitative research tends to use a range of methods for ensuring the reliability and validating of the research process (Barbour, 2001; Mays & Pope, 1995) including coding. Some of these methods were used in this study, for example group discussion and mutual agreement upon codes; the reason for this was to reduce researcher bias and encourage some level of "consistency" (Armstrong *et al.*, 1997, p. 599). Other methods, such as statistical calculations of inter-coder agreement, were not used; this is because although quantitative measures of inter-rater reliability can be helpful for enhancing study rigour (Mays & Pope, 1995), it is not essential to the qualitative research process whereby its appropriateness has been historically debated (Armstrong *et al.*, 1997). According to Cook (2012), different types of reliability measures can be used in qualitative research if researchers establish 'a deliberate understanding of when they are appropriate and what they add to the investigation' (p. 99). In this study, quantitative/statistical inter-rater reliability was not explicitly

stated as a requirement of the framework method; instead the approach aims to be explicit, whereby the analytical methodology and process by which conclusions are reached are accessible to individuals other than primary researchers (Pope *et al.*, 2000; Ritchie & Spencer, 1994).

The standards by which qualitative analyses are judged are important and this study aimed to adhere Yardley's (2000) criteria for rigorous and valid qualitative research as well as undertaking verification strategies as outlined by Morse *et al.* (2002) and taking a reflexive stance (Malterud, 2001).

### *2.7 Ethical considerations*

Ethical approval for this study was obtained from the London Bloomsbury NHS National Research Ethics Committee (reference: 11/LO/0497). All participants were recruited from Guys and St Thomas's NHS Foundation Trust; approval for this recruitment was obtained following study registration with the Trust's research and development office (reference: Study 11/LO/0497).

# Chapter 3: RESULTS

A total of 44 men expressed interest in this study: 5 declined interview, 5 were unreachable by phone, 4 did not meet eligibility criteria, 4 could not participate for practical reasons (e.g. travel difficulties) and 7 expressed interest subsequent to thematic saturation and so were not recruited. Thus, a total of 19 men were interviewed; all interviews were transcribed in full and included in qualitative analysis.

## *3.1 Socio-demographics, clinical characteristics and quantitative findings*

Socio-demographic and clinical information for the 19 interviewed men is displayed in table 3.1. The sample included 15 white men (13 white British, 1 white English and 1 white Irish man) and 4 black British men with Afro-Caribbean descent. Men had an average age of 68.6 years (SD 9.4), whereby the youngest man was aged 45-years old and the eldest was aged 84-years old. All men were heterosexual, most were married or living with a partner (79%) and retired (68%). The proportion of men with a degree or professional qualification (37%) was similar to that of men with no qualifications (32%). The majority of men were on an androgen withdrawal treatment (63%) whereby the average weekly frequency of hot flushes and night sweats (as measured by the first two items of the HFRS) were 34.5 (SD=26.6) and 22.2 (SD=25.8) respectively. The average period that men had been experiencing HF/NS was 16.9 months (SD=16.1), that is 1.4 years; this ranged from 3 months to 60 months. Most men had received no treatment for symptoms (79%). Average problem-ratings as calculated from the HFRS were 4.8 (SD=2.4) and average illness threat was 47.5 (SD=11.5). Illness threat was determined by scores collated from 8 dimensions of illness; data for each of these dimensions collected using the B-IPQ are shown in table 3.2.

| | | Mean (Range) | Standard deviation, SD |
|---|---|---|---|
| Age, *years* | | 68.6 (45-84) | 9.4 |
| Duration with HF/NS, *months* | | 16.9 (3-60) | 16.1 |
| Hot flush frequency, *number per week* | | 34.5 (3-84) | 26.6 |
| Night sweat frequency, *number per week* | | 22.2 (0-112) | 25.8 |
| Problem ratings, *1-10* | | 4.8 (1-9) | 2.4 |
| B-IPQ illness threat, *0-80* | | 47.5 (26-72) | 11.5 |
| | | **n** | **%** |
| Ethnicity | White British | 13 | 68% |
| | White English | 1 | 5% |
| | White Irish | 1 | 5% |
| | Black British | 4 | 21% |
| Relationship Status | Married / Living with Partner | 15 | 79% |
| | Widowed | 2 | 11% |
| | Divorced / Separated | 1 | 5% |
| | Other | 1 | 5% |
| Sexual Orientation | Heterosexual | 19 | 100% |
| Education | O-level/Standard grade | 4 | 21% |
| | Higher/A-level/National grade | 1 | 5% |
| | Degree/Professional Qualification | 7 | 37% |
| | No Qualifications | 6 | 32% |
| | Other | 1 | 5% |
| Employment | Retired | 13 | 68% |
| | Unable to work | 2 | 11% |
| | Working full-time / Self-employed | 3 | 16% |
| | At home not looking | 1 | 5% |
| Religion | Church of England | 6 | 32% |
| | Roman Catholic | 2 | 11% |
| | Christian | 2 | 11% |
| | Catholic | 1 | 5% |
| | Anglican | 1 | 5% |
| | Atheist | 1 | 5% |
| | Adventist | 1 | 5% |
| | Undisclosed | 3 | 16% |
| | None | 2 | 11% |
| Stage of prostate cancer | Metastatic | 5 | 26% |
| | Locally advanced | 3 | 16% |
| | Localised | 4 | 21% |
| | Other | 1 | 5% |
| | Unknown | 6 | 32% |
| Hormone Treatment | Androgen withdrawal | 12 | 63% |
| | Other | 4 | 21% |
| | Unknown | 3 | 16% |
| Receipt of treatment for HF/NS | Yes | 3 | 16% |
| | No | 15 | 79% |
| | Unknown | 1 | 5% |

**Table 3.1: Socio-demographic information and clinical data for participants (n=19)**

| *Scale* | *Items* | *Mean* | *Standard deviation* |
|---|---|---|---|
| **B-IPQ** | **Consequence** | 6.5 | 3.2 |
| | **Timeline** | 7.9 | 2.2 |
| | **Personal control** | 1.7 | 1.9 |
| | **Treatment control** | 8.1 | 2.8 |
| | **Identity** | 5.8 | 2.1 |
| | **Concern** | 7.5 | 2.5 |
| | **Coherence** | 6.6 | 3.5 |
| | **Emotional representation** | 6.2 | 3.0 |
| | | | |

**Table 3.2: Average ratings (with standard deviations) for illness dimensions from the Brief-Illness Perception Questionnaire (B-IPQ) across participants (n=19)**

High ratings on individual items from the B-IPQ were judged as those above 5, whereas low ratings were judged as those below 5. High scores indicate more threatening illness perceptions than low scores for all domains except personal control, treatment control and coherence, for which high scores reflect less threat than low scores. On average, men in this study reported low personal control over their prostate cancer, but high scores in all other domains; thus, men tended to view the following dimensions of their prostate cancer as threatening: consequence, timeline, personal control, identity, concern and emotion representation.

### *3.2 Thematic findings*

It was not possible to conduct separate thematic analyses by ethnicity due to the small proportion of black British men recruited (thematic saturation would have been unlikely). However, themes generated across all participants revealed a range of experiences associated with HF/NS. The following thematic categories were identified, along with one miscellaneous category: (a) the characteristics of HF/NS; (b) cognitions about HF/NS; (c) awareness and knowledge about HF/NS; (d) emotional reactions to HF/NS; (e) HF/NS triggers, maintainers and alleviators; (f) management of HF/NS; (g) sources of support for HF/NS; (h) cognitions about prostate cancer and (i) general cognitive self-perceptions. The core thematic category in this study related to cognitions about HF/NS; the majority of themes were related to this central theme.

Table 3.3 is the thematic framework index generated from the framework approach and illustrates the superordinate and subordinate themes that constitute each of the aforementioned thematic categories. These thematic categories are described in turn, whereby charts, figures displaying associations and dimensions of themes and extracts from interviews are used to illustrate participants' views.

### 3.2.1 Characteristics of HF/NS

Every man described their HF/NS and key themes related to the nature of somatic sensations; characteristics of HF/NS influenced men's judgements about the perceived intensity and salience of these sensations, which are explored in greater detail within the central theme of cognitions about HF/NS.

The majority of men reported a rise in temperature and sweating when they experienced HF/NS, whereby some men identified specific body regions that were affected by these sensations; these regions tended to be the head, face and neck, although other regions included the stomach and abdomen, the genitals, the heart and upper chest, the ankles and legs and arms. Other descriptions of somatic changes included breathing difficulties, the perception of emitting heat, experiencing tiredness and a lack of energy, feeling faint, experiencing tightness around the stomach region, feeling "like your body's not yours", experiencing headaches and nausea and experiencing paraesthesia and itchiness. Some men reported a change in physical appearance, whereby they described flushes affecting facial complexion and/or the neck.

Flushes with a sudden onset and gradual offset were described by some men. Others described a gradual onset to their flushes, which either began all over or in the head or body. A small proportion described experiencing sensations that forewarned them of a flush and allowed them to prepare for one. Some of these men also expressed difficulties at times distinguishing a flush from other activities that involve sweating or exposure to high temperatures; other men also had this difficulty, although one man

**Table 3.3: Thematic framework index illustrating all themes generated in this study**

**Characteristics of HF/NS**

- *Bodily sensations*
- *Change in physical appearance (+/-)*
- *Onset-offset speed*
- *Difficulties distinguishing flushes from other activities*
- *Duration*
- *Frequency*
- *Onset*
- *Different types*

**Cognitions about HF/NS**

- *Cognitions about HF/NS and the self*
  - Beliefs about the impact of HF/NS on masculinity
  - Change in self since HF/NS began (+/-)
  - Without HF/NS back to normal self
  - Embarrassment about HF/NS
  - Self-perceptions during HF/NS
  - Perceived control over HF/NS
  - Lucky/Unlucky
  - Coming to terms with HF/NS
- *Cognitions about HF/NS and others*
  - Attitude towards salience of flushes
  - Beliefs about healthcare professionals actions
  - Beliefs about other's reactions to HF/NS
  - Attitudes towards HF/NS and women
  - Considering how others cope with HF/NS
- *Cognitions about HF/NS in general*
  - Usefulness
  - Beliefs about HF/NS in men vs. women
  - Beliefs about why HF/NS don't affect every man
  - Curiosity about triggers
  - Noticing flush irregularities, related thoughts

**Awareness and knowledge about HF/NS**

- Awareness *that hormone treatment causes flushes*
- *Initial reactions – expectations*
- *Confusion due to being unaware about flushes*
- *Benefits of insight*
- *Becoming more aware of flush occurrences*
- *Uncertainty about experiencing NS*
- *Awareness of HF/NS treatments (+/-)*

**Emotional reaction to HF/NS**

- *Annoyance and frustration*
- *Aggression/ irritability*
- *Fear linked to confusion/anxiety*
- *Shame*
- *Guilt*
- *Grateful*
- *Happiness/ Humour*
- *Hope*
- *Relief*
- *Surprise*
- *Difficulties recalling affect*
- *Expressing little emotion*

**HF/NS triggers, maintainers or alleviators**

- *Presence of triggers (+/-)*
- *Exercise*
- *Context – temperature*
- *Time of day*
- *Long-term treatment*
- *Multiple treatments*
- *Patterns to flushes*
- *Preoccupation/distraction*
- *Mood*

**Management of HF/NS**

- *Behavioural strategies*
  - Practical strategies for managing flushes
  - Compensating for flush-related sleep disturbance
  - Disclosure
  - Not help-seeking/ Treatment for flushes not sought or refused
  - Seeking external sources of support
  - Seeking advice from family and friends
  - Awareness of unhelpful behaviours
  - Social avoidance
- *Cognitive strategies*
  - Relaxing and staying calm
  - Ignoring flushes
  - Willing flushes away
  - Not thinking negatively
  - Externalising flushes
  - Cheer oneself up
- *Limitations of strategies*
- *No or few strategies*

**Continuation of table 3.3**

| Sources of support for HF/NS | General cognitive self-perceptions |
|---|---|
| *Attitude towards treatments for HF/NS*<br>*Perceived sources of support*<br>*Attitude towards talking with others with similar problems*<br>*HF/NS treatment preferences* | *Impact of comorbid illnesses*<br>*Perceived decline in capabilities*<br>*Changes resulting from age*<br>*Changes resulting from less work stress*<br>*Belief in control over one's body*<br>*Attitudes towards emotional coping* |
| **Cognitions about prostate cancer** | **Miscellaneous** |
| *Symptoms of prostate cancer and other treatment side-effects*<br>*Prostate cancer-related self-perceptions*<br>*Consideration of one's own vitality*<br>*Considering cancer and death*<br>*Considering cancer survivors/ learning from others with cancer*<br>*The fight against cancer*<br>*Trusting in religion to help prostate cancer*<br>*Not feeling alone with prostate cancer*<br>*Not mentioning prostate cancer to others*<br>*Unawareness of prostate cancer diagnosis*<br>*Not feeling ill*<br>*Questioning oneself about seeking the prostate cancer diagnosis* | *Involvement in research trial for prostate cancer treatment*<br>*Experience of flush during interview*<br>*Wanting to help with HF/NS research* |

**N.B. (+/-) refers to presence or absence**

reported that his flushes differed so dramatically from such situations that he never misinterpreted his flushes:

> *…'cause I like to do the cooking indoors, so if I'm doing the cooking then… you know you think oh you're over a hot stove you know, so it's quite hot… so you could say to yourself oh it's the cooking that's making me… but it's not it's a different feeling CE [researcher's name] all together, it's an internal feeling as opposed to laying in the sun and being hot, it's totally different all together. (Pp019, lines 234-238)*

Men's descriptions of the frequency of HF/NS were variable; one man reported experiencing a night sweat every 20-30 minutes, whereas another reported experiencing night sweats once or twice a night. Men also described variability in their own descriptions of flushes, with one man stating: "…could be say, say another

number a day like you know … you don't have the same amount every day" (Pp031, lines 712-716).

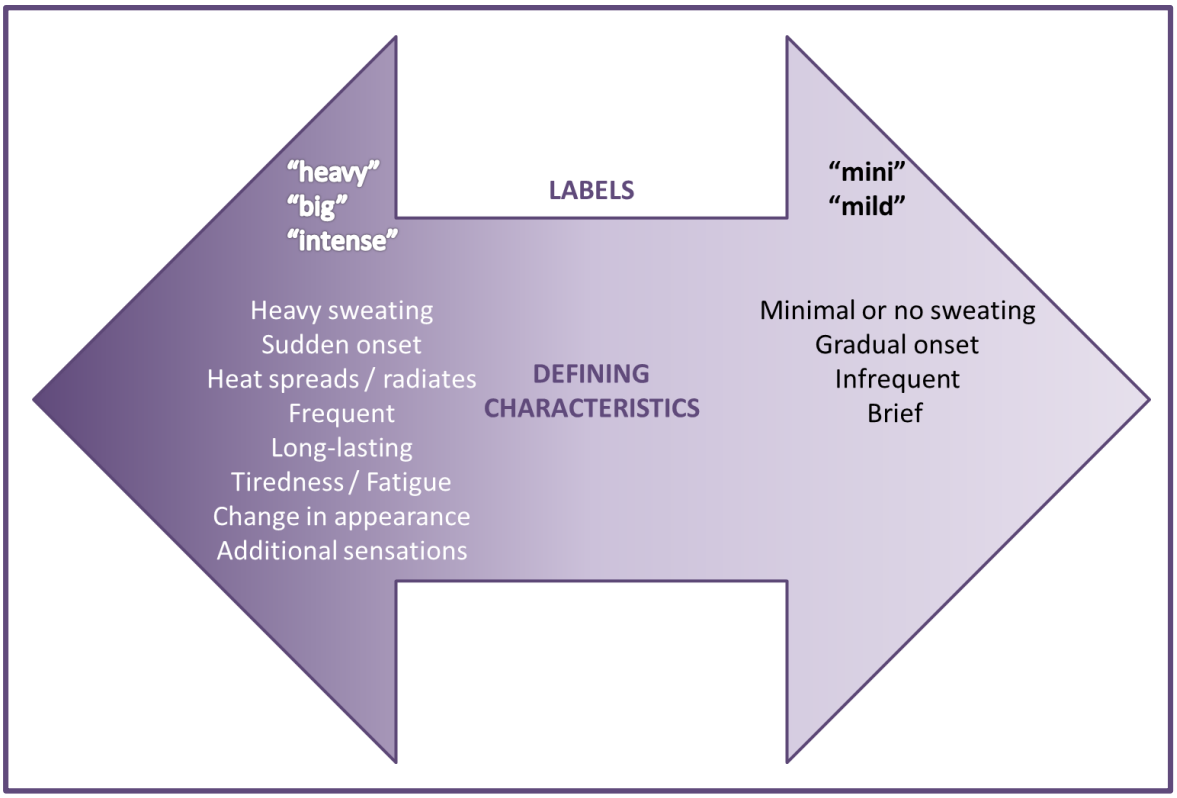


**Figure 3.1: Categories of flushes according to HF/NS characteristics**

Most men described flushes lasting for less than five minutes, some described flushes that could go on for up to 10 minutes and others described occasions when they had experienced flushes that had lasted for up to 20 minutes.

The characteristics of HF/NS that have been described led some men to categorise their flushes as "heavy", "big" or "intense" or as "mini" or "mild" according to varying physical manifestations; figure 3.1 illustrates the characteristics men associated with these two different types of flushes. This bi-dimensional view affected men's judgements and reactions to flushes, for example, "mild" flushes were perceived as relatively easier to endure than "heavy" flushes and one man explained that he tended to discount "mini" flushes as hot flushes all together. For a small proportion of men these different categories of flushes represented the difference between hot flushes

and night sweats, whereby night sweats tended to be described as the more "intense" flush.

A subtheme unrelated to the aforementioned definitions of flushes was men's descriptions of the initial onset of their hot flushes. Descriptions all made reference to the commencement of hormone treatment; a similar proportion of men described a sudden onset of HF/NS in the days or weeks following hormone treatment to those that reported a delayed onset in which HF/NS began months after hormone treatment. This association between HF/NS onset and the commencement of hormone treatment and the duration between these events interacted with men's awareness about HF/NS and their anticipation of flushes; some men with a delayed HF/NS onset did not expect their flushes and could not recall being given information about the possibility of flushes following hormone treatment when their flushes began and thus their initial cognitions about flushes were influenced by this. Some men described being concerned by initial symptoms because of an initial lack of awareness of their cause.

### 3.2.2 Cognitions about HF/NS

Men had a number of cognitions relating HF/NS and their effects; this was a central theme and was associated in some way with most other superordinate themes. Cognitions comprised of the following three superordinate themes each with their own sub-themes: cognitions about the self, cognitions about others and general cognitions about HF/NS.

#### *Cognitions about the self*

Some men expressed beliefs about the impact of HF/NS on their masculinity; approximately half of all men believed that HF/NS were side effects commonly associated with women rather than men with one man describing them as "women's things" (Pp005, line 86), a small proportion of men viewed flushes as emasculating and

some jokingly expressed beliefs that HF/NS were a sign of turning into or behaving like a woman:

> *… and uh XXXX [wife] said to me y-you're having a hot flush and I said certainly not you see, however they carried on and uh she persuaded me more or less and this is when I said uh I rather think this is very unmanly to have such things … because it's unmanly you see (laughs). (Pp005, lines 6-9)*

> *…so I said well I've joined the club then ain't I (laughs) … I couldn't make it out... I thought I changed me sex or something (laughs) … you know like as I say like you know I've joined your club… I'm the hot flush boy, like another lady you know as in me change has come late in life, you know… (Pp031, lines 295-325)*

Some men identified changes in themselves since the onset of flushes some of which were linked to general changes they perceived in themselves unrelated to HF/NS (general cognitive self-perceptions) and others linked to changes due to prostate cancer (prostate cancer related self-perceptions). Men described alterations in typical emotional reactions and mannerisms, for example one man commented "I don't think I'm as patient as I was…" (Pp010, line 322-323) and others described becoming more irritable and aggressive.

One man explained that changes were exclusively emotional, saying flushes affected "… only the way I feel, you understand" (Pp016, line 302). Another man described self-consciousness and changes in the way he viewed himself compared to others:

> *…it just makes me feel like I'm the, I'm the odd one out aren't I, I'm different from the general populous, 'cause everyone's gone back to business, everyone's just doing whatever they do you know… what's wrong with this erm gentleman here. (Pp017, lines 232-234)*

This man described feeling "anxious" around others as a result of his self-consciousness and some of his reported behavioural strategies for managing HF/NS included social avoidance.

Other changes in behaviour and approaches to various daily activities as a means of managing HF/NS were reported by men:

*I've adjusted myself… by slowing down… actually slowing my body down in virtually everything I do… um… if I do the garden I would crack round with the lawnmower, bang, crash, wallop, done, finished… you know I think, you know I'll take my time on it, you know, do the weeding you know and I think I'll do halve of them today then you know… uh… I wouldn't now run… to get the bus, I'd say uh hang on there's another bus sort of thing… (Pp019, lines 339-344)*

*I have to do that… make sure I have a little gap between getting to the [golf] ball and actually playing it, because uh otherwise… which I never used to have to do… you know I could just walk up to it and whack it before but… not anymore. (Pp024, lines 56-59)*

Some men reported no changes in themselves since the onset of HF/NS. One man had at one point received medical treatment for HF/NS and described how life had improved when he was on medication and he described feeling "back to normal… back to your normal self again" (Pp031, line 567) before this medication was stopped.

Embarrassment about HF/NS was a theme that emerged for some men; this was mostly associated with flushes that were noticeable to others and raised concern about the conclusions others might reach about the reasons for flushes:

*…you're talking to someone like I'm talking to you now, I'm sweating here now, it's not the heat... but then maybe after a while you know it will just cool down… and then you know people say oh you're nervous man, I don't know why you're nervous, why are you sweating… a little bit embarrassing, it is… (Pp032, lines 447-450)*

*Well I feel shame … other people might think that I'm… I'm very, very sick. (Pp016, lines 540-544)*

Other reasons for embarrassment related to being unprepared for flushes and not wanting inquisition about them, for example one man explained that "sometimes too much questions can make you feel embarrassed because you don't want to tell everybody everything" (Pp032, lines 289-291). Embarrassment was also associated with perceptions that flushes were unpleasant to others and discouraged others from seeking proximity, the use of "unmanly" strategies for cooling down and the location in which flushes occur, whereby some men identified particular situations in which flushes would be more embarrassing, for example:

> *…birthdays or friends who'd invite you to a restaurant or to um wedding reception or weddings and everything like that and you really feel embarrassed because sometimes, many times they would ask you to give a speech or a toast and I will be sitting here, even like in church, you're sitting there and nothing and as I get up, you just, I could feel it coming on so while I'm up there nobody's sweating but I will have my hanky doing this (gestures wiping face) so you feel embarrassed (Pp032, lines 311-317)*

Thus, to some extent, embarrassment influenced the management strategies men adopted for their flushes in public and, in some cases, influenced the extent to which men engaged in social events.

All men described their experiences during HF/NS. During hot flushes, many self-perceptions related to feelings of discomfort due to feeling hot and sweaty, irritability and being "put out", "exhausted" or "overcome", with some men reporting feelings of shame, disgust and anxiety. Some men reported experiencing reduced motivational drive and functionality, whereas others reported concentrating on a task until flushes passed. Self-perceptions during night sweats were reported by the majority of men, most of which included feelings of being hot, being irritable, frustrated or angry and being disturbed from their sleep.

Most men gave an account of their perceived level of control over HF/NS; all described feelings related to powerlessness.

> *Not much I can…you can't really do anything about it … You can't relax, you get tired you go to bed you can't sleep, you have to get up… just makes everything ache… it's just horrible… but what's the alternative? (Pp010, lines 119-133)*

> *Yeah I don't know what you can do, it just happens, I mean, it-it's, so far as I'm aware it's…not controllable, uncontrollable, I mean it… it's an automatic trigger. (Pp002, lines 64-65)*

Some of these men identified powerlessness that was closely associated with acceptance of their flushes.

> *To be honest none, I don't think about it… this is the way I sort of look at things, I don't think about it, there's nothing I can do about it so you just accept it... (Pp020, lines 156-157)*

Other men described powerlessness that was linked with tolerance and endurance of an undesirable experience.

> *There's no alternative is there, 'cause if I don't have the treatment the cancer will just grow… it's err… it comes down to the hot flushes or dead… not really much of an option there is it? … Um…well it just has to be, it's just the way it is… 'cause there's nothing, nothing I can do about it… other than lie between them, I mean that would just be a ridiculous thing not to do err … (Pp010, lines 137-144)*
>
> *Um well if it-it if it's going to cure… then you know fine I'll put up with it but um… there isn't any alternative is there, really… (Pp013, lines 223-224)*

Some men considered themselves lucky when they considered the severity of their flushes and judged them to be less severe than that of others or when they viewed flushes as a minor consequence given the other more devastating outcomes that are associated with having cancer:

> *I've got off the hook, because I'm… the thing is I'm so well after what I could have been with cancer, having a cancerous growth and having a big operation and having it all taken away… (Pp012, lines 346-348)*

Others came to the opposite conclusion believing themselves as unlucky for being among the proportion of men who experienced HF/NS rather than being among the few who do not have such symptoms.

All men described the extent to which they had come to terms with their flushes; this was conveyed via 8 subthemes: acceptance, adjustment, attitudes to flushes and hormone treatment, the impact of early experiences and background these attitudes, beliefs about the future of flushes, the impact of flushes on cognitive processes and physical activities and judgements about the severity of flushes. Figure 3.2 displays typologies of the way in which these subthemes were expressed by men when considering perceptions of the extent to which flushes were perceived as problematic and the degree to which they had come to terms with flushes.

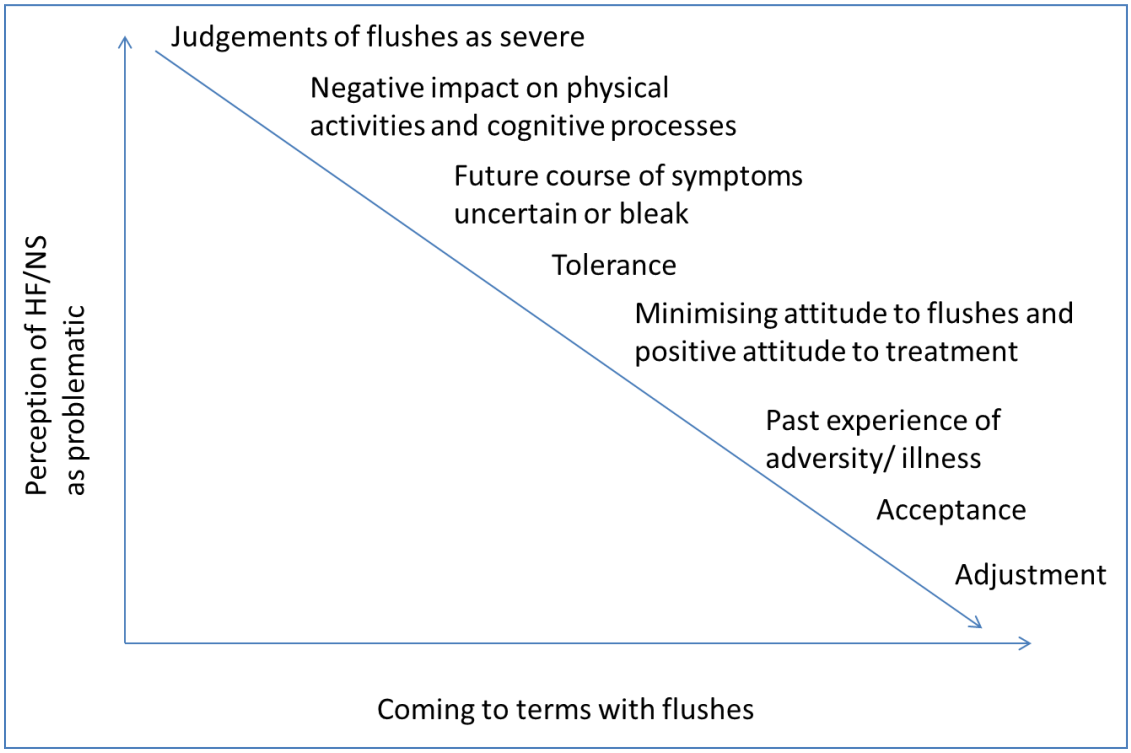


**Figure 3.2: Typologies of accommodating attitudes to HF/NS**

Adjustment included becoming "used to" flushes, beginning to "cope with them", learning "to deal with it" or flushes becoming "something to expect"; men described this process in different ways, for example one man likened his adjustment to the way in which one might adjust to other bodily ailments and another likened his adjustment to pregnancy:

> *You just think …but now that this is part of my erm… you know my make up like various other things that… that my body and…you know like (laughs) … [l]ike a sore knee or … [a] bad toe or I don't know, you know the other odd aches and pains you just think, this is part of my err…(tut) err my body's um make up now. (Pp001, 109-115)*

> *…it's a bigger part of your life, I guess it's like being pregnant (laughs). (Pp002, line 240)*

Others described specific ways in which they had made adjustments and some men identified a shift in the way that they had perceived their flushes in the past compared to how they currently viewed flushes:

> *…nowadays it's just become part of the norm of my life so in the early part it used to really really drive me up the wall… (Pp017, lines 177-178)*

One man reported difficulties adjusting to flushes and another reported that he had yet to fully adjust, saying "it's something you've got to learn to live with but I've not lived with them long" (Pp014, lines 133-134). Most men who described adjusting to flushes also described acceptance of their flushes.

The influence of background and upbringing on attitudes towards flushes, hormone treatment and prostate cancer were described by several men. Men who had parents, relatives or partners who had dealt with adversity and/or illness by persevering felt they had adopted a similar approach to their own difficulties:

> *Well I suppose really it's you-your upbringing, like I mean… in the war I was evacuated… yeah I was an evacuee in the war and I never come back uh… until all the bombing was all finished, well my mother and father lived in XXXX during all the bombing, the day bombing, the night bombing and at the bottom of their road was the docks, which they was after, now in the morning they had to get up and go to work, which they did do… see as I said to you like they done that, and they was in their fifties then when they done all that, I was only a boy, fourteen, fifteen like, they done all that so… you learn from your mother and father so if they can do it… (Pp031, lines 428-435)*

Other men described elements of their own personal experiences that had helped them to adopt helpful coping strategies, such as learning "not to worry" or developing the strength to cope with adverse situations.

Attitudes to flushes were largely associated with the discomfort caused by symptoms; most men described their flushes as "uncomfortable" and/or "unpleasant", whereby unpleasantness was indicated by other words including "horrible", and "disgusting". Men tended to describe attitudes towards flushes that suggested they were unconcerned about them, for example:

> *It's as simple as that… it doesn't worry me, it doesn't concern me much in any way, shape or form. (Pp031, lines 607-608)*

Some men viewed flushes as "minor" or "trivial" events which were an

"inconvenience", an "irritation", an "annoyance", a "nuisance" and/ or a "headache". Among these men were some who viewed their flushes as "manageable" and some who believed that their flushes were a minor concern relative to other problems including concerns about how long one has to live and thoughts about fighting cancer and ridding oneself of the disease.

Most men approached flushes with attitudes that were associated with a reluctance to make a "big deal" about flushes, whereby men spoke of trying not to "dwell" on flushes or "worry", "talk" or "fuss" about them, and with attitudes to flushes that minimised them, whereby men tended to remind themselves that flushes would not "last long", that they would "pass", "settle" or "disintegrate" fairly quickly or that they would "come and go". Flushes were described as amusing by some men, whereby one man described mixed attitudes towards flushes, including that of amusement and annoyance.

Flushes were also described as "weird", "peculiar" or "strange" sensations, for example one man said: "…it just comes down and drifts away… it's as if it's like your soul… you know, very peculiar, you know…" (Pp019, lines 380-381). A small number expressed thoughts about when the next would recur and some had thoughts such as "here we go again" or "oh no not another one". One man described a negative initial attitude towards his flushes:

> *[I was] not-not particularly pleased obviously (Pp005, line 25)*
>
> *I didn't want to accept it at the start of them … (Pp005, line 558)*

There were men who held positive attitudes to treatment and flushes including seeing flushes as a sign of treatment effectiveness, for example one man spoke of feeling reassured by flushes:

> *Well I was reassured when somebody told me that they're, they're… for me getting hot flushes looks as if this treatment's been working … if the hormones are working and that's the only problem that I've got … I'm on a winner… so I'm looking at that as uh positives… to the treatment… (Pp012, lines 419-424)*

Treatment with hormone injections was associated with being alive and being able to continue being active. The costs of hormone treatment were considered alongside the

benefits and most men concluded that the treatment was necessary for survival; the extract below is an example of one man's decision regarding treatment:

> *I mean I understand, when I met one of the doctors and they said to me like you've got to start this treatment you know…um and there are a couple of problems that men face, anxiety problems which are around the waist if you get a belly you know and your breasts… which they do you know… there! But uh XXXX [a friend with prostate cancer] and I just looked at it as if crikey if that is all you've got to put up with… a bit of larger breasts… and the tummy… and you're gonna [sic] live then so what! You know… just put up with it… (Pp019, lines 51-58)*

Some men held negative attitudes to flushes and treatment; one man reported having hormone treatment but dreading hormone injections because of the severity of flushes that he expected to follow and other men reported feeling that the hormone treatment was having negative effects on their bodies, for example:

> *…you're already putting your body under stress with the hormone treatment… probably it's putting the body under stress it's an unnatural thing… (Pp014, lines 767-769)*

> *Yeah… well I'd like to think I feel like superman rather than… this you know… I always expect treatment um to make you better rather than worse, I know I suppose medically it's making me better but feeling-wise it's making me worse… 'cause I can't do things you know… (Pp018, lines 390-393)*

For these men, negative attitudes to flushes and treatment were accompanied by powerlessness as described above and a need to tolerate their situation in order to survive.

The majority of men reported beliefs about the future of HF/NS; many believed that flushes would continue only for the duration of hormone treatment and for most this was between 2 to 3 years, whereas for others this ranged from a matter of months to an unknown period. Some men's attitudes to flushes for the duration of treatment were positive, for example:

> *I would imagine I'm going to be on Zoladex probably for the rest of my life, for however long it lasts … I'll have hot flushes and I'll have to learn to cope with them… but I can't foresee, I can't really see them getting any worse than they are now… (Pp021, lines 279-283)*

Other reactions were less positive, for example:

> *very frustrating… very annoying, I mean you just don't see an end to it, you know where…you just think all the time oh I'm intrigued when this is gonna [sic] be happening, you know all the time I'm on it… (Pp010, lines 121-123)*

> *As long as I have the treatment…I can't see any, I can't see any change I mean I've had enough of them now to know that this is still ongoing, it's not like my body is getting used to it and adapting, it's just not, it's just constantly happening … (Pp010, lines 218-220)*

There were men who believed that flushes could continue following cessation of hormone treatment, whereby one man was uncertain about this and another also held a belief that his flushes were "not going to last forever" (Pp012, line 57).

Descriptions of flushes that interfered with cognitive processes were given by most men, whereby negative effects on mood states and sleeping and waking were reported:

> *… and depressed because of it, they get to the stage where in fact, and that's rare, where they are that severe that you… yo-it's both tiring and irritating, and um that is debilitating (Pp002, lines 353-355)*

> *… they said the sleep would be uh be affected by the hormone treatment and that but I didn't realise it would be so… bad you know, I can't remember the last time I had a good night's kip. (Pp018, lines 107-109)*

A small proportion of men described negative effects of flushes on concentration, work efficiency and the ability to relax. One man identified the way in which flushes interfered with sexual intimacy with his wife:

> *'Cause a couple of times when we've sort of tried, you get a hot flush and just oh hang a minute, hang on a minute, no, no I can't uh and it just takes away any energy or anything you've got… you know you just feel uncomfortable, it's just horrible. (Pp010, lines 621-623)*

The extent to which flushes were judges as severe was influenced by beliefs about how

much flushes interfered with life, along with beliefs about the severity of flushes compared to others with flushes, other side effects and other situations, the intensity of the characteristics associated with flushes and the effects of flushes on others. Figure 3.3 illustrates the characteristics of these themes that were associated with more or less severe flushes.

The majority of men believed that flushes were of low severity. Men believed that flushes largely did not interfere with their lives because they did not entirely prevent them from continuing with personal interests and daily activities, for example:

> *Well they don't, I-you know, they don't affect me that, that much really, you know, I'm not err… it hasn't ruined my life or anything like that. (Pp001, lines 457-458)*

> *Not as yet, I'm not going to stop playing golf just because I'm having a hot sweat or a hot flush (laughs) no… I won't let it change my life, in that way. (Pp024, lines 249-250)*

Interference caused by flushes was minimal for these men and included disruption to the cognitive processes and activities outlined previously. Flushes were perceived as "not that bad" whereby this was communicated in various other ways, including: "not particularly debilitating", "not worried", "not… distressing". Some of these men, along with others, judged flushes to be equivalent to or less problematic than other side-effects of hormone treatment; other side-effects included impotence, loss of libido, reduced energy, weakness and fatigue, increased appetite and weight-gain, diarrhoea, low or depressed mood, headaches, concentration difficulties, joint pain, increased irritability and/or aggression and indecisiveness. Most men reported experiencing one or more of these side-effects.

Some men compared flushes with other physical illnesses that they had experienced and/or with other difficult situations and most believed that flushes were far less distressing. Comparisons of flushes with others with flushes and/ or others in life more generally were also made and men concluded that they were in a more fortunate position.

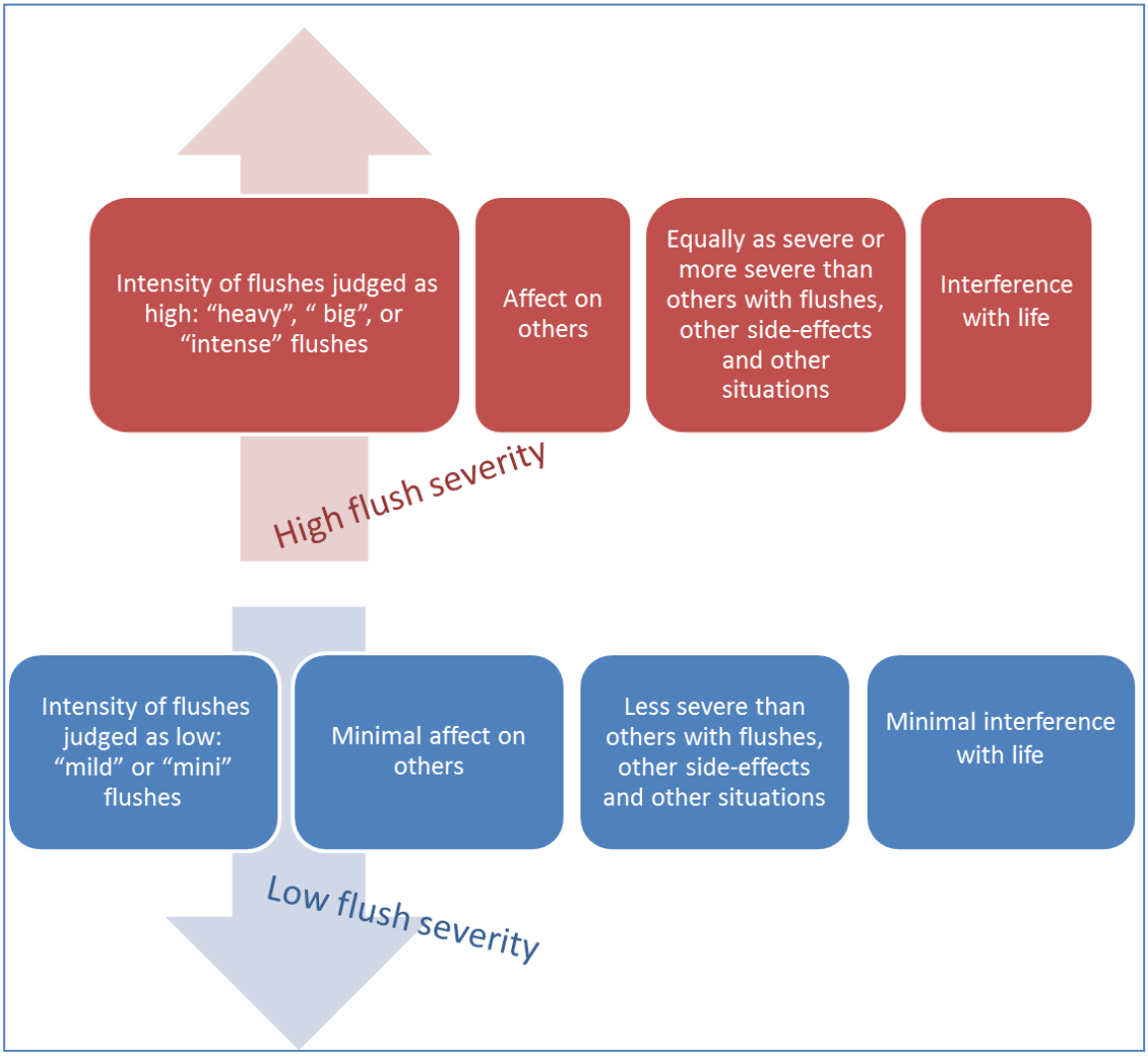


**Figure 3.3: Characteristics of low and high flush severity reported by men**

Most men judged any flushes that led to any amount of sweating, “soaking” or feeling “clammy” as more severe than those that involved no sweating; this along with other physical characteristics of flushes distinguished “heavy” flushes from “mild” ones as described previously (see fig. 3.1). One man reported experiencing a severe flush in which he experienced tiredness and another reported that severe flushes would affect his appearance: “if it’s severe my face can flush and my neck will flush” (Pp002, lines 101-102). Some men described particular contexts in which flushes were more intense, including being in bed, sitting down in the evenings and being in humid environments.

A number of men believed that flushes had an unpleasant effect on those close them; most believed these effects to be minimal. Some of these effects on others included

the symptoms of flushes themselves, the behaviours or mood changes associated with flushes or the sleep disturbance caused by night sweats, for example:

> *Yeah…which annoys XXXX [partner] because she doesn't like the window left open… but I have to… if I don't feel that breeze coming across, it's not good. (Pp010, lines 157-158)*
>
> *… I'm probably not so easy to live with as I ought to be. (Pp005, line 218)*
>
> *Well since all this business started, my wife sleeps in the other room, I mean we always sleep, slept together before but uh… she doesn't want, she doesn't want to… be disturbed so uh… (Pp024, lines 425-427)*

***Cognitions about others***

Men expressed explicit views about the salience of HF/NS to others; some men were unconcerned by others noticing their flushes, whereby reasons included "not caring" about what others think and not being self-conscious, being more concerned with the positive effects of treatment and being unconcerned about informing others about flushes. There were some men who preferred that their flushes went unnoticed by others and this affected the strategies that they undertook to manage their flushes. These men described feelings of discomfort when others did notice flushes and some made attempts to disguise their flushes. For example, one man outlined the way he is able to avoid others noticing his flushes and how he might feel in settings that made avoidance more difficult:

> *You know there's lots, there's lots of different areas I mean uh I travel on me own you know going to work on me own and uh I don't get too, too tied up with getting, getting into big groups um… so as I say if you were stuck on a train… it wouldn't be good… if you were working in an office, in an open environment where you're staying and you do not always know the people you might just think, they might not be noticeable but you might just, you might have that feeling like you know you think oh God… they'll see he's not right at the moment … I drive to work and if something happens to me, it's only me… (Pp012, lines 559-574)*

Some of the men who preferred unnoticeable flushes, along with other men, held beliefs that there would be undesirable consequences if others were aware of their

flushes, these included: the spread of misinformation, possible inquisition, others believing that flushes were contagious, being treated differently and receipt of unwanted sympathy.

All men expressed views about the reactions of healthcare professionals involved in their cancer care to their HF/NS, whereby perceived reactions influenced awareness and knowledge of HF/NS. Some men reported receiving professional advice for their flushes, such as tips on how to cool down and advice about the way in which diet can affect flushes. They reported being given "ideas", receiving knowledgeable and kind care and being advised on and prescribed treatment for flushes. Men judged such reactions as helpful. Other men reported they had not received any advice.

Some men felt that healthcare professionals were limited in the information they could provide and in what they could do about HF/NS; they believed that although professionals provided some knowledge, they were ultimately powerless to help with HF/NS and such beliefs were associated with men not explicitly seeking advice for flushes or not being informed of treatments for flushes for example:

> *I think along the line to be honest I think everybody's been brilliant … they haven't got any answers, there's no point talking to somebody who can't give you any answers, they've already said that they don't know what the effects are so… (Pp010, lines 493-502)*

One man felt that he was unable to access help for his flushes because of difficulties seeing his GP. This man also felt that the advice he had received from healthcare professionals about his prostate cancer conflicted with advice from other professionals who were providing him with care for a pre-existing health problem.

All men gave an account of the way that they thought other people perceived them during HF/NS. Many felt that their flushes largely went unnoticed, however some of these men felt that flushes were more noticeable in certain situations, such as during a meal or other social situations. Some men felt that their flushes were always noticeable. During HF/NS, many men felt that they were perceived by others as different to their usual selves. One man thought that people saw him as "…an idiot (laughs) … either that or I'm extremely embarrassed about something that uh they

haven't worked out yet (laughs)…" (Pp005, lines 271-289). For a small proportion of men, close proximity to others during flushes was intolerable due to their severity, thus they believed others might view them as "moody" (Pp017, line 296) or "a person to stay away from" (Pp010, line 396), for example:

> *Well generally when you're out I just don't, you're in a close proxy of people I don't like to be around them, I feel like they're adding to the intense heat and maybe they are adding to the intense heat 'cause there's all body heat and so forth so I'm very sort of aware of not wanting to be in a crowd ... (Pp017, lines 27-30)*
>
> *I can't be around people I just can't… it just takes over the whole of me body which I don't wanna [sic] be around people it makes me more moody… (Pp017, lines 295-296)*

Other men felt they were being perceived as foolish, "grumpy", "making too much fuss", dishonest, anxious or displaying "abnormal behaviour"; a number of men felt that people would believe that there was "something wrong" with them or that they were unwell or even in one man's case that he was "dying" (Pp016, line 538). Some of these men also believed that certain people saw them as their normal selves, whereby any perceptions by others during HF/NS were not stable or could be altered depending on the nature of their relationship with those others.

There were men who felt that flushes did not affect how others perceived them, for example one man commented:

> *…nah they just see me as XXXX [name] like you know what I mean… they don't notice me at all any different… they don't see me any different… even my nephews, they don't see me any different when I'm having a flush like you know. (Pp031, lines 457-485)*

Most men described typical reactions to HF/NS displayed by family and friends. Most reactions were considered helpful such as being sympathetic and tolerant, providing support and practical solutions such as dietary advice, getting a glass of water or encouraging men to relax. One man described the way in which his wife had helped him without realising:

> *Well she doesn't exactly uh she doesn't exactly know she's helping me, right, so over the years I've watched her uh having her hot flushes due to her menopause and I've not exactly studied her but taken notice of what she does to cool herself down and help the situation… (Pp021, lines 465-467)*

Other reactions included acceptance, concern, being jocular about flushes and sharing information about one's own ailments. There were men who held views that there was little family and friends could do to help with flushes, for example one man said: "there's nothing they can help you with is there really um I mean sympathy doesn't stop the flush um…" (Pp013, lines 506-507).

A small proportion of men believed that other's reactions to flushes were that of understanding and empathy, whereby some felt that close friends and family who were aware of their flushes would tend not to comment or highlight them. Some men felt that family and friend's reactions to flushes and associated effects could be mixed, for example:

> *I guess irritability from me um… they're either very good at accepting that or they're not very good depending on how they feel that day so…can't blame them for that… (Pp002, lines 504-506)*

> *Couple of times at work yeah, granted I don't really know, they sit down the other end rather than come and talk… some would but you know talk to me, doesn't bother me (Pp018, lines 146-147)*

Reactions from family and friends that were unsympathetic or evoked feelings of discomfort were also reported, such as talking about their own problems, being unavailable and not wanting to be in close proximity to men when flushes occur.

When describing exclusively women's reactions, men reported that women's reactions to flushes included some of the above, including sympathy and the use of humour. A small proportion of men reported that women could be "callous" or would purposefully mention flushes to "pee you off". Some reported that women tended give advice about how to manage flushes, for example, one man commented: "women (laughs) constantly give you advice (laughs) ... suddenly brand names and things…that I could hardly just… I couldn't remember any of them…" (Pp006, lines 445-450). Some men reported than women could be dismissive of men's flushes whereby they would

make reference to their own experiences. Others reported that they had discussed flushes with women, whereby one man found this "strange" and "funny" because "…probably not many people would know that one of the side effects of treatment is flushes" (Pp006, lines 251-252).

Few men made reference to how they felt about their flushes being compared with women's flushes, of the men who were asked about this, they all expressed a lack of concern about such a comparison, with one man saying "it's a similar symptom" (Pp014, line 471). Men were also unconcerned about the humour and jokes that women applied to their flushes; in one case a man was given a sanitary towel by a group of women and found this humorous:

> *I would joke about it … it didn't you know uh bother me much at all… oh no … They laughed, they laughed well you know and one of the women said here you are have one of these (laughs). (Pp031, lines 323-330)*

Approximately half of men were amused by the women's jocular reactions to their flushes. This emotional reaction was common among men who described flushes that impacted on their masculinity and was also related to the way in which men adjusted to their flushes; attitudes towards flushes that minimised flushes using humour were associated with men who had come to terms with their flushes.

A small number of men considered how others with flushes had coped and used this information to inform their own management of flushes; for example, one man's father also had prostate cancer and he reported: "I never heard him complaining at all but whether he'd suffered from it but just kept it to himself I don't know… 'cause I can't ask, he died about three years ago now so I can't ask him (laughs)." (Pp014, lines 424-426).

***Cognitions in general***

Approximately half of all men viewed flushes as useful in some way, which influenced their attitudes towards flushes. A number of men saw flushes as positive sign because

it meant that they were “alive”, others saw flushes as a source of inside information that allowed them to empathise with their wives and other women who had experienced the menopause, for example:

> *…from a men’s point of view, not realising how uncomfortable it is for women (laughs) which is uh… something that most men would never experience … I do yeah (laughs) appreciate it… yeah only just that it’s quite a strange thing to realise because … I’ve obviously heard it for the flushes that women have but… I don’t think they fully appreciate whatever they go through I mean to the extent as I said earlier that they are sometimes on HRT and all sorts of things … I’ve seen a lot really how dramatic it… it could be… (Pp006, lines 324-340)*

Some men also joked about appreciating HF/NS in the winter or when temperatures were lower because it “keeps you warm” (Pp031, line 9). One man commented: “if I’m feeling cold and it happens I’m grateful… sorry there is a positive you know I’d forgotten, I’m very grateful you know.” (Pp002, lines 480-481). Another man joked: “in fact probably it [flushes] might help me lose a bit of weight I don’t know (laughs)…” (Pp021, lines 48-49).

There were men who compared their flushes with women’s menopausal flushes. A small proportion described their views of male and female flushes as very separate, although others saw these flushes as equivalent, whereby the causal factor was the only identified difference; one man concluded:

> *…that now is a same, similar very similar effect of what I’m getting… the only difference between the two a man has been induced… (Pp014, lines 860-862)*

One man viewed his flushes as slightly worse than women’s flushes because of the qualitative differences between his flushes and those reported to him by his wife and his aunt.

Reasons were generated as to why some men did not experience flushes and one man concluded:

> *…perhaps it depends how much testerone [sic] you have in your body to start with I don’t know… it’s obviously you’re talking about the whole chemical make-*

*up of your body and not the action you're going to get I've always uh one of the conclusions I've come to it depends how much testerone [sic] you've got in your body me being an athlete and must be that I've done things that would be considered very masculine compared with what most women would do and that might have an effect, my high levels of testerone [sic] in my life… some of it (laughs) shared over the years perhaps I have had a decline so that may imply that uh maybe I have (laughs)… (Pp014, lines 594-614)*

Some men reported that they would think about flushes when not experiencing them. One man spoke of wondering about triggers for his flushes:

*I-I always feel I wonder what, I wonder what brought that on, that's what I, that's what I always think… you know I think is it because I put that fire on or… um really I'd been cold anyway me hands are cold, you know? (Pp026, lines 748-750)*

Others spoke of being more aware of irregularities to their flushes and generating possible reasons for any changes to their usual pattern of flushes. There were men who identified irregularities linked to particular contexts such as temperature changes and certain locations and some men also considered the duration since the last hormone injection and the impact of this on irregular flushes, for example:

*I don't get as many hot sweats when I'm away in hot weather which is funny or it could, it also… I'd have to really monitor it better but it could also be the time of erm… particularly when I've had the actual drug because when you have the drug in the beginning you have fewer hot sweats and as it gets later towards you need it again you have more hot sweats… so it all depends on when I've gone away on holiday… (Pp017, lines 210-214)*

### 3.2.3 Awareness and knowledge

This theme interacted with emotional reactions to flushes, cognitions about flushes and management strategies. Although most men attributed their HF/NS to hormone treatment, some came to this conclusion by a process of deduction:

*…the only thing I can think of is… the Zoladex… is bringing it on… you know… because before I started the treatment, I never had it… so it's either the Zoladex*

*or the radiotherapy … [a]lthough if it was the radiotherapy, that didn't start… I think 'til after the first month or two… and the flushes started before that, the treatment… so it… I would imagine that it's the hormones that are causing the problem you know… (Pp019, lines 44-51)*

Approximately half of all men reported being unprepared for experiencing HF/NS, whereby symptoms were unexpected due to various reasons, including being uninformed of possible treatment side effects. As described above, some men spoke of having been informed of possible treatment side-effects but not being able to recall this information when flushes began; one man could not recall warnings of possible flushes but spoke of possibly receiving this information and distancing himself from it because "it wasn't going to apply to me" (Pp005, line 358).

Men's reports of unexpected HF/NS were in some cases associated with feelings of surprise and with concern, which affected subsequent thoughts about the effects of flushes:

*I didn't realise that they were hot flushes, I just felt that there's something wrong with me in actual fact you know because… they were coming…pretty fast you know… (Pp019, lines 4-6)*

Some men described confusion due to the lack of awareness about HF/NS as a possible side-effect and in some cases this confusion was associated with fear. This confusion influenced cognitions about perceived changes in the self since the onset of HF/NS and perceived control over flushes; for example, one man questioned the way that he had changed due to flushes: "[t]o be truthful, I ask myself how I got this way … [i]t never troubled me in the last twenty years until… until now …" (Pp016, lines 530-532). This man also described feeling powerless to alter his situation. Similar confusion was reported in relation to another treatment side effect (lack of sexual desire).

Some men described the benefits of insight into HF/NS and of knowing that they were a possibility following hormone treatment. For example one man commented: "…because I know the um circumstances behind that you know to not feel so terrified of it…" (Pp032, lines 545-546).

Men described being informed of the possible side effects of hormone treatment either through discussion with healthcare professionals or through their own investigations and reading. A small proportion of men attempted to delineate the specific mechanisms involved and made links between receipt of treatment with a female hormone and the experience of symptoms similar to menopausal symptoms:

> *I suppose yeah 'cause … as far as I know I'm being fed a female hormone, so as far as I'm aware it's causing the same effects as women having their … menopause, which is a natural thing when their oestrogen drops isn't it… we're being fed oestrogen which is not natural to males so it is a chemical I suppose a chemical reaction… (Pp014, lines 589-593)*

Some reported that the process of recording flushes for this study increased their awareness of their HF/NS, whereby in both cases they came to conclude that they had more flushes than they had originally thought but had overlooked some of these flushes due to misattribution. One of these men and another man described sensations that resembled night sweats but were uncertain about attributing them to night sweats:

> *Um…well I don't know to be honest I mean…I woke up this morning…I woke to…covered in sweat, I always do-whether that's to do with the way I sl-I sleep with the…with the erm duvet pulled right over my head (laughs) … But I always wake up very…err…sweaty … but whether that's to do with the… with the drugs or not I'm not quite sure … I really don't know whether I have them or not. (Pp001, lines 302-319)*

Management strategies in terms of help-seeking for HF/NS were influenced by men's limited awareness of the existence of treatments to manage HF/NS. Some men reported not being told of any treatments or not researching or asking about any such treatment. Some men expressed beliefs that treatments for HF/NS did not exist and so did not attempt to seek them; one man described feeling that "there didn't seem to be much that could be done about it" (Pp001, lines 370-371) and another commented: "…as there isn't [any suitable treatment]… there's no point… get on with it basically…" (Pp010, line 509). Five men reported an awareness of some form of treatment for their flushes although few could specifically name any.

### 3.2.4 Emotional reactions to HF/NS

Emotions associated with flushes interacted with four main themes: cognitions about HF/NS, management strategies, awareness and knowledge and sources of support. Annoyance and frustration, humour, surprise and fear were the most reported emotional reactions to HF/NS. Annoyance and frustration tended to be associated with having to engage in behaviours such as clothing removal to cope with flushes, being woken by night sweats and/or the "inability to carry on normally" (Pp014, line 163) when having a flush during daily activities, having more severe flushes or flushes in certain environments. Reactions to flushes involving humour are described elsewhere and tended to be associated with both men's and other's reactions to flushes, such as joking about them. Some men gave accounts of experiencing surprise in response to flushes and, in every case, this occurred in response to men's initial experiences of flushes. Fear was linked to initial confusion about the cause for flushes in those men who were unaware that flushes were a possible side-effect of treatment; for example, one man had fears that his flushes would "probably kill me or something" (Pp016, line 209) and another gave an account of the anxious thoughts that ran through his mind during early flushes:

> *…you wonder what is taking part in your body what is happening, is it um… is it gone too far, can they help … so it's a bit of a puzzle and you're … wondering what is going to happen if so how far has it gone, can they help me whatever I'm going to go through and all this, all these things that come into your mind they start there first… because the hot flushes was as I said, it's, you feel scared when it's coming on ... (Pp032, lines 88-93)*

One man also reported anxiety related to being around people when having his flushes.

Lesser described emotional reactions to HF/NS included gratefulness, guilt, hope, relief and shame. Gratefulness was associated with receipt of the initial diagnosis and subsequent treatment that was perceived as rapid and life-preserving. Relief was reported in relation to successful treatment for flushes in the few men who received pharmacological treatment for their flushes. A general relief associated with the non-occurrence of flushes was also described; one man spoke of finally being able to fall

asleep after a day of recurrent flushes: “I slept … I just went, it was just, it was like a relief… it was like a release I should say…” (Pp002, lines 366-367). One man, upon experiencing flushes, felt guilty about how he had treated his wife’s flushes:

> *… because I’ve taken the mickey out of her all those years thinking it was… erm… not that she was putting it on, but exaggerating with the flushes… [a]nd I know absolutely definitely now that she wasn’t exaggerating… really that was quite bad on my part… you know. (Pp019, lines 227-231)*

All descriptions of hope were linked to a desire for flushes to cease. Shame was described by one man, whereby this was related to experiencing a flush in public and his perception that others would see him as sick. Feelings of happiness were reported by one man and associated with noticing when flushes have not occurred for some time. Some men reporting aggression and irritability could not identify specific triggers, but associated these feelings with a general emotional change caused by flushes and/or hormone treatment.

There were reports of difficulties recalling initial emotional reactions to flushes and one man described distracting himself with other activities during flushes and not expressing his emotional reactions about them to prevent others from pitying him; he reported that this was the same way that he learned to deal with his initial reactions to his cancer diagnosis because he saw himself as “a fighter” (Pp012) and reported an aversion to receiving pity.

### 3.2.5 HF/NS triggers, maintainers or alleviators

The majority of men described possible triggers for their flushes, these included: being indoors and less active, being active, having a meal or hot drink containing caffeine, sudden movements or making a rapid transition from activity to inactivity, doing something stressful such as work or disciplining children, anxiety, drinking alcohol and eating sweet or spicy foods. One man reported experiencing flushes whenever holding his newborn granddaughter.

Some men found that their flushes occurred during physical exercise; one man described how he continued to have them even while exercising in the gym:

> *… when you're training as well it still… your sweats still come onto of the training (laughs) so it's kind of like really intense… (Pp017, lines 77-79)*

Approximately half of all men identified changes in ambient temperature as possible triggers for flushes and the same proportion of men identified time of day as a possible trigger, whereby most reported flushes being worse in the early evening or at night; one man tried to explain why this might be:

> *I've never had a real sweaty one during the day… it's only at night and… but you know you've got uh you're night clothes on top, you've got you're pyjamas on um so uh… you're warmer in bed so it's probably why you get a more sweaty flush than uh… during the day… (Pp013, lines 431-434)*

One man reported that the longer the length of time one spends on hormone treatment, the greater this impacts on mood:

> *Well you put up with things for a certain length of time then the longer it goes on it just… really gets you down, a little bit you know… you don't really see a light at the end of the tunnel if you start talking about years, if you're talking about months you can see the end of the tunnel then it's not so bad but um … it is affecting me … I can't but help thinking a little bit about it and the affect it has on me. (Pp014, lines 775-781)*

This same man described the way in which multiple treatments, such as concurrent radiotherapy and hormone injections, were more for his body to "get over" (Pp014, line 786). Another man described multiple treatments, in his case treatment for heart problems and hormone treatment, as confusing, he said: "So I'm sitting there looking at it is it all evolved into one or have I got this problem and that problem you know." (Pp018, lines 370-371).

There were men who identified patterns to their flushes: most identified a decline in the severity of flushes over time; some reported an increase in severity and frequency

following a hormone injection and some reported a reverse pattern whereby flushes were less severe following a hormone injection and became increasingly worse over time.

Some men reported that their flushes were less likely to occur when they were preoccupied or busy and a small proportion believed that their mood states could prolong HF/NS; they identified annoyance, irritation and worry as possible maintainers for their flushes.

> *… if there is something that I'm worrying about I could find it comes more regular, lasted longer more than when I'm relaxed… (Pp032, lines 389-391)*

For some men their conviction in the potential triggers, maintainers and alleviators that they described influenced the extent to which they engaged in certain behaviours and activities to manage their flushes and influenced their reporting of changes to HF/NS characteristics. Others believed that these factors were merely possibilities and did little to influence behaviour or perceptions of flushes; such attitudes to triggers, maintainers and alleviators influenced less helpful behavioural reactions.

### 3.2.6 Management of HF/NS

All men reported behavioural strategies to manage their flushes, with some also describing cognitive strategies, most men described limitation to strategies and some reported using no or very few strategies; this theme therefore consists of these four superordinate categories, each of which with subthemes (see table 3.3).

#### *Behavioural strategies*

All men engaged in practical strategies to manage their flushes, whereby some strategies had been influenced by information from healthcare professionals; commonly described strategies included clothing removal, wiping sweat, pausing

activities and waiting for flushes to pass, making adjustments to diet or lifestyle, seeking out cold areas and getting fresh air by using a fan or opening windows. Some men reported drinking water to cool down and some gave an account of the way in which they made changes to the type of clothing they wore (e.g. wearing thinner layers). Less common strategies included attempts to identify triggers and recording or keeping track of flushes to identify "… timeframes … to work within…" (Pp017, lines 44-45), following medical advice, withdrawing from situations in which flushes occur, drinking tea, showering or bathing, problem-solving and planning ahead, going to bed, carrying a water spray or immersing oneself in water and making changes to bedding material.

There were men who reported undertaking compensatory strategies to cope with the sleep disturbance associated with night sweats. Napping during the day was the most commonly reported compensatory strategy. Some men tried to go back to sleep immediately after night sweats and others described "combining" side-effects:

> *… what I sort of do then, like as I did last night, I combine the two… when I'm woke up with an hot flush (laughs) I went out and had a wee (laughs)… you know. (Pp031, lines 355-357)*

Disclosure of experiencing a flush was also described as a management strategy:

> *Um…I just say I'm getting hot, I have to take me jumper off or what me coat or whatever, that's all you know… so they say… if I'm in their uh say a dining room, they say oh it's hot in here, I say oh no it's not it's my condition, my condition I say that to 'em but then I say I'm not too worried about it you know. (Pp026, lines 625-628)*

There were men who expressed a reluctance to do this, whereby reasons related to embarrassment about flushes and a desire to protect one's privacy; for example, some men spoke of not wanting to "expose" themselves, "broadcast" their "business" or not wanting to "explain everything to everybody" (Pp032, line 246) because "that's my business" (Pp020, line 272) or "it's none of their business" (Pp012, lines 135-136). Most men reported that they had shared information about their flushes with

someone, for example, healthcare professionals, close friends, family members or other individuals where necessary and in some cases in order to seek support.

Some men reported that they had not sought help for their flushes, reasons for this related to men perceiving flushes as something that they had to "accept" and "get on with" and also perceptions that little could be done to help with flushes. Many men did report help-seeking or information-seeking, whereby some men did this when they first began having flushes and were confused about their experiences and others expressed desires or intentions to seek help following interview; for example, one man commented: "I mean, I might take it up the next time… I see my consultant…" (Pp012, line 447). Another man said: "but I kind of would like to speak to somebody and maybe they could advise me whether there was anything…" (Pp006, lines 229-230). Some men sought advice for their flushes from family and friends; one man had a daughter who was a nurse and other men chose to seek advice from close friends, friends with flushes or partners with flushes.

Pharmacological treatment for HF/NS was refused by some men, due to concerns about further treatment side-effects or concerns about the use of medications for other disorders being used to treat flushes. These treatments were not sought by some men due to a lack of awareness about treatment availability and due to a desire not to seek medication for flushes.

There were men who reported being aware of engaging in behaviours that were unhelpful for their HF/NS, such as drinking tea and coffee, ceasing the use of herbal remedies perceived to be helpful, eating spicy foods and choosing not to change bed materials that were known to be aggravating flushes. This was associated with conviction in HF/NS triggers and maintainers and consideration of the limitations of management strategies; for example, one man weighed up his conviction in a hot flush trigger and the effect that engaging in a management strategy to avoid this trigger would have on him:

> *I-well I mean from what I've read in the pamphlets about errm… spicy food, um that sort of thing maybe because I like spicy food… so that may be contributing*

*towards it I don't know… I can't eat bland food, if it's bland I can't eat it (laughs). (Pp020, lines 118-120)*

A small proportion of men described in engaging in behavioural avoidance of social situations due to their flushes. One of these men explained that his family no longer do grocery shopping in order to avoid the crowds, instead having their shopping delivered.

***Cognitive strategies***

Some men reported relaxing and staying calm as a means of managing their HF/NS, whereby comments such as "most times I just let 'em float over me and relax…" (Pp008, lines 195-196) and "[y]eah I'll just have a puff and a blow, sit down, yeah and just let it go." (Pp018, line 303) were common. There were men who described learning to "ignore" flushes, take "no notice" of them or treat them as if they "are not there".

Other cognitive strategies that were less reported included: willing flushes away, whereby one man said he "just think[s] 'go away!' and sometimes they do…" (Pp008, line 194) and avoiding negative thinking, whereby the same man said "there's no point thinking oh God… I just think to myself right 2015 I'll be free of this and maybe it won't come back…" (Pp008, lines 587-588). One man externalised his flushes, saying "I call it "it" because that's what I've named it now…" (Pp019, line 113) and another described how he cheered himself up and made himself "happy" by singing to himself to prevent his flushes from becoming an annoyance.

***Limitations of strategies***

Many men reported limitations to practical behavioural strategies for cooling themselves down. These limitations included: being unable to remove clothing to the extent that one would at home in certain locations, such as on the tube or in a

meeting; the unpredictability of the effectiveness of strategies, whereby some days they may be effective but others they may not; alternating between being too hot due to flushes and too cold due to cooling strategies and being unable to reduce internal temperatures with strategies that target external body regions, whereby one man commented:

> *I've gone out and got a…a cold flannel and put it across your forehead and around your neck… but it's not that type of… heat … it's like if you could get the flannel inside your body… yeah. (Pp019, lines 323-326)*

Some men reported limitations to relaxing as a way to manage flushes, whereby one man explained that he could only relax when lying down but could not do this everywhere:

> *Well I can't relax, I'd have to lie on the floor (laughs)… so if I'm in Sainsbury they'd think what's the matter with him? (Pp008, lines 325-326)*

Other men had beliefs that HF/NS "…come when they come…" (Pp017, line 60) and that a flush "goes when it wants to go" (pP019, line 111); these men perceived flushes as uncontrollable and saw relaxation as limited by this.

***No or few strategies***

Some men described feeling that they did little to manage their flushes and some reported doing "nothing whatsoever" (Pp012, line 373). This is despite all of these men providing at least one strategy that they used when having flushes. The minimising of management strategies was associated with beliefs about perceived control over HF/NS; most men believed they were powerless to stop flushes and so had little confidence in the strategies that they did undertake as a means of effectively managing their flushes.

### 3.2.7 Sources of support for HF/NS

Some men expressed interest in treatment for HF/NS, with some expressing eagerness and others expressing a willingness to consider any available treatments. There were men who were only interested in treatments with "proven" success. Men expressed concerns about possible interactions between multiple treatments, whereby some of these men were only interested in treatments that would not interfere with their hormone treatment and one man had concerns about interactions with his medication for a pre-existing medical condition.

Two men had retrospectively received medication to treat their HF/NS, however in both cases this was not a prolonged treatment. One man reported no success with this treatment and reported unusual bodily sensations:" I could tell when you take the tablet it's not the same feeling in your body when you don't take it …" (Pp032, lines 639-640). The other man found that one medication "more or less completely stopped it [flushes] like, they was [sic] terrific" (Pp031, line 17); however this treatment was stopped unexpectedly leading to the return of flushes and confusion about the reason behind this medical decision. This man was placed on another medication to manage his flushes but he reported no success with this second treatment and felt it limited his alcohol intake

There were men who reported a preference for medication to treat their HF/NS, whereby most of these men, in addition to others, expressly had no preference for psychological treatments if this included a group. Men who preferred treatment with medication gave reasons relating to a desire to completely remove flushes via "physical" change rather than getting help to reduce them. Reasons why psychological treatments were not preferred included beliefs about group therapies and support groups, whereby some men felt that they would be unable to express themselves; one man felt this could be due to "some character that wants to take over the show…" (Pp012, line 467). Other reasons related to negative attitudes towards talking as a form of treatment for flushes and a mere preference for medication. Some men preferred not to take medication for flushes, some felt that self-help would be of possible benefit and some expressed interest in complementary or homeopathic remedies.

Some men identified sources of support for flushes that did not involve treatment. Some men mentioned the helpfulness of attending, both formal and informally organised, PCSGs. One man said his wife and pet dog were supportive, another explained that observing his wife's flushes had been helpful and two men described communicating with other men in hospital while awaiting various consultations; one of these men described how he found this to be a positive experience:

> *I thought I might be having sweats and then I got talking to the lads in the what I used to call the tiddler's club … we swapped stories… (Pp008, lines 86-92)*
>
> *…there's a whole captive audience there of gentlemen all of whom are getting sweats or other problems … I was quite happy going there 'cause they lighten the, 'cause you have to go there every single day for thirty-seven days except for weekends … (Pp008, lines 218-239)*

There were men who believed that it could be helpful to talk to other people with similar problems to themselves. One man commented:

> *…there's something you can relate to about … the way you are and your problems… and there might be feedback from that same person whose had the same treatment and you kind of you know you kind of link up what… you know you learn from what they've said … (Pp012, lines 290-293)*

Other men did not feel that such discussions would be beneficial to them; some men preferred not to discuss their problems, with one man saying "I don't like these talky talky groups, I don't like 'em, I don't like airing my stuff out in public…" (Pp010, lines 557-558), and other men could not see any benefits in "sitting talking to people" (Pp020, line 490). One man thought he would find it hard to articulate how he is able to cope with his flushes, commenting:

> *… it's very difficult, how do you communicate how you cope with it if it's within yourself, it's very difficult to get that across it's something I think really I think really that a trained uh psychologist or psychiatrist or something like that would be able to do better … (Pp021, lines 555-557)*

### 3.2.8 Cognitions about prostate cancer

All men reported having thoughts specifically about prostate cancer, whereby a number of subthemes emerged (as listed in table 3.3). The most commonly mentioned subthemes were: descriptions of the symptoms associated with prostate and the side-effects of radical treatments to manage the disease, accounts of alterations in self-perceptions following diagnosis and reports of the way in which vitality was considered following diagnosis.

Many men described prostate cancer symptoms and treatment side-effects other than those caused by pharmacological hormone treatments. All of these men gave an account of having "bladder problems", issues with "waterworks" or urinary urgency; they attributed these problems to prostate cancer. There were men with a detailed understanding of the process by which bladder problems were caused by prostatic growth and one man explained how this problem had led to his diagnosis:

> *… my bladder problems … [t]hey're a side effect of prostate cancer and although they are a side effect that is the symptom that…alerted the doctors to find out I'd got cancer in the first place and I'd had that for ten years apparently… (Pp008, lines 201-206)*

Side-effects caused by radical treatments such as radiotherapy or prostatectomy reported by men included lethargy and lack of energy, low mood, lack of sexual desire, physical sensations, such as pain and an "itchy tummy" (Pp019, line 154), and physical deterioration, whereby one man described "loss of hair" (Pp020, line 67), another expressed concern about his fingernails "peeling" (Pp014, line 369) and another spoke of his skin changing colour: "it changed the colour of my skin… one part dark…" (Pp016, lines 617-618).

Many men gave accounts of changes in the way they viewed themselves following the adaptations they had been forced to make in their lives after being diagnosed and undergoing treatments for prostate cancer; these changes were associated with HF/NS cognitions about themselves and incorporated views of themselves prior to hormone treatment. Most of these men spoke of being "active", "fit", "energetic" and "positive"

prior to their experience of prostate cancer; they reported notable changes in these self-perceptions following diagnosis and treatment. Adaptations to HF/NS such as using a slower pace at times when they come on were signs of changes in themselves resulting from prostate cancer. Some men specifically felt that their physical strength had declined as a result of their prostatectomies and one man spoke of disruption to confidence in his belief that his cancer was under control, which affected his ability to carry on with his life as usual:

> *… it hits your confidence a bit… so you're not sure, you're not sure, you might get a good reading now but you're not sure if there, is it permanently gone you just don't know do you … so you're never, you're never sure… you're uncertain yourself … (Pp012, lines 207-220)*

Other men identified feeling restricted by prostate cancer, whereby one man spoke of the way that he was unable to make plans because of the prospective treatments he might need:

> *… I feel a little bit restricted … you got to have time [sic] where you can't really travel round the world when you've got to have some treatment done or an operation… (Pp014, lines 377-385)*

Alternatively, one man spoke of developing "a more positive attitude" (Pp021, line 350) after being diagnosed with prostate cancer because of beliefs that negativity would lead to a faster death; he viewed all aspects of his prostate cancer, including HF/NS, differently as a result of this attitudinal shift.

There were men who reported considering their vitality, whereby some spoke of their likelihood of recovery following diagnosis and gave accounts of their thoughts about not surviving. Men made judgements about survival based on what they had been told by healthcare professionals, by comparing themselves to long-living family members or others with cancer. Some men had thoughts about not seeing grandchildren growing up or wanting to be "closer to people" (Pp019, line 357). One man spoke about the way in which his "long-term attitude to things" was affected:

> *… I think I was thinking about buying a car, it's just an example of something I had to do, and uh I didn't know, I mean I'd decided on the car I wanted and I thought shall I buy it or shan't I because I'm thinking to meself [sic] thinking that's a lot of money I could be leaving the other half, to my partner… (Pp014, lines 400-404)*

Other men described feelings of apprehension or concerns about their likelihood of survival, whereas others expressed hope for recovery or thoughts about the future course of their disease alongside certainty about their contentment in the present, for example one man commented:

> *… I'm not going to worry because I come looking forward knowing that it will get worse but as it is there now I'm happy within… and then I may even die I don't die of cancer or something else but then I know as long as I live it will get worse, I'm getting older and um… how long they will be able to control it I don't know… (Pp032, lines 267-271)*

Other, less commonly described, thoughts about prostate cancer included: thoughts about cancer and death, whereby some men described coming across others who had died from cancer; accounts of learning from or being aware of others with cancer who had survived the disease and men's thoughts about of their battle with cancer. One man spoke of the way in which praying and trusting in his religion has helped him to survive for longer with his prostate cancer. Another man described not feeling alone in his battle with prostate cancer: "…we're all in this together you know, there's me and these few blokes and thirty-five thousand others somewhere out in the country…" (Pp008, lines 277-279). A small proportion of men reported not informing their children or grandchildren of their prostate cancer diagnosis, whereby one man said he didn't want to "bother them with it" (Pp026, line 638). One man described being unsure that he had a prostate cancer diagnosis and another man reported that he did not feel unwell despite having cancer.

Doubts were raised by some men about having sought their diagnoses given the problems that followed treatment, with one man saying "… I wished I'd… left well alone … well I'm eighty in a couple, two or three days-time and uh… um… I've had quite a good life (laughs)." (Pp013, lines 256-284) and another saying "…makes me

think sometimes was it worth getting diagnosed you know 'cause I was fitter beforehand…" (Pp018, lines 70-72).

### 3.2.9 General cognitive self-perceptions

Men's self-perceptions included observations of changes in themselves that included but went beyond any perceived changes associated with HF/NS and prostate cancer. Some men identified physical illnesses that were affecting their lives; for most their illnesses were additional problems to HF/NS and prostate cancer but for one man this was not the case, whereby he had diabetes and found that when this was controlled, it did not affect him or influence his flushes.

Men reported a general decline in capabilities, whereby declines occurred in "strenuous" daily activities, such as gardening, washing the car, exercising or engaging in sports, and "functionality" in terms of recalling diarised events and being able to work. Some of these men, along with others, attributed changes in their lives, such as physical problems and declining capabilities, to the effects of age. One man commented:

> *I know I'm getting old now you know 'cause I've always said nah I'm not but I know you know… it's sinking in a little bit… when you know that you can't do what you used to do. (Pp018, lines 575-576)*

One man described a positive change in his life; he described having less "daily aggravation" (Pp002, lines 284-285) in his life because he was self-employed and worked from home so avoided the stress associated with using public transport.

A small proportion of men described self-perceptions associated with perceived control over their bodies; whereby one man explained how he preferred not to take medication for migraines because he believed he could control symptoms by remaining relaxed and calm.

Beliefs relating to emotional coping were also described by men; one man attributed changes in his mood as normal, whereby he commented: "… you're going to get mood changes in a normal day and normal health." (Pp014, lines 181-182). Another man minimised certain emotional experiences, such as stress and worry, due to a belief that such emotions were not experienced by his parents who endured bombing during war and so were "invented" (Pp031, line 103).

### *3.3 Associations between thematic categories and quantitative measures*

Case analyses were conducted to consider similarities and differences across the nine thematic categories among men selected on the basis of their HFRS and B-IPQ scores; charts were constructed to aid these analyses and are displayed in figures 3.4 and 3.5.

Figure 3.4 displays a summary chart of the entries made across themes by a group of three men with the most problematic flushes (HFRS problem-ratings of ≥7.5) and figure 3.5 displays a similar chart for another group of three men with the least problematic flushes (HFRS problem-ratings of ≤2.5). There were four men with illness threat scores of ≥60; two of these men also had high HFRS problem-ratings. Thus, for ease of case analysis, themes among the two men with high illness threat scores and high HFRS problem-ratings have been considered together with those men with only high HFRS problem-ratings; rows for men with concurrent high illness threat and HFRS problem-rating scores are highlighted in figure 3.4.

*Participant characteristics*

The extent to which participant characteristics such as demographic variables (e.g. age, ethnicity) and illness characteristics (e.g. prostate cancer stage, hormone treatment type) interacted with HF/NS problem-ratings and illness threat were not examined statistically due to the small sample size included in this study and the focus on qualitative analyses. Figures 3.4 and 3.5 include these participant characteristics and there are noticeable trends; in the group of three men with high HF/NS problem-ratings/illness threat, two were notably younger than the average age of the entire

sample (with one man notably older) and two were black British. Hormone treatment types and prostate cancer stages were variable among this group and these data were missing for one man. Among the three men with low HF/NS problem-ratings, all men were white British/English, did not differ notably from the average age of the sample and had metastatic prostate cancer. Two of the three men were also receiving androgen withdrawal treatments.

*HF/NS Characteristics*

Those men with high problem-ratings/illness threat had a tendency to describe "heavy" flushes that involved excessive sweating and heat spreading across or emanating from the body. Men with low problem-ratings described "mild" flushes that were "hot", brief or infrequent with minimal sweating.

*Cognitions about HF/NS*

Cognitions about HF/NS associated with the self were focused on the negative impact of flushes in most men in the high problem-ratings/illness threat group; interference caused by flushes was highlighted alongside undesired perceived changes in one's own abilities and self-perceptions, powerlessness over flushes and an uncertain or negative future with flushes. Conversely, the impact of flushes was minimised in those men with low problem-ratings and powerlessness over flushes was associated with a need to adjust and accept them.

In the group of men with high problem-ratings/illness threat, cognitions about HF/NS relating to others focused on flushes being noticeable to others, resulting in unfavourable perceptions and/or a desire to conceal flushes due to shame or embarrassment. These men had beliefs that health professionals were unable to help. In those with low problem-ratings, there were also beliefs that unfavourable perceptions by others could result from noticeable flushes; however there were common beliefs that flushes were unnoticeable, whereby men held beliefs that noticeable flushes could also result in humour or little change in other's perceptions of them. Receipt of professional advice varied among these men and beliefs about the limitations of professional help were also present.

**Figure 3.4: Chart of thematic entries for men with high HFRS problem-ratings**

| | | Characteristics of HF/NS | Awareness and knowledge | Cognitions about HF/NS: | | | Prostate cancer cognitions |
|---|---|---|---|---|---|---|---|
| | | | | Self | Others | General | |
| **Participant** (age, ethnicity, cancer stage, hormone treatment type) | **Pp010** (51, WB, localised, androgen withdrawal) | Includes sweating, headaches and feeling faint; "radiating heat"; draining; lasts 2-4mins but "seems like a long time"; sometimes occurs every 20-30mins at night | Flushes expected, "pre-warned"; severity unexpected; aware of cause; unaware of treatments for flushes | Flushes as "horrible"; interference; reduced functionality; masculinity affected; dreading injections; powerlessness-tolerance; future with them bleak; limited adjustment | Others notice; change in appearance; perceived as irritable, someone to avoid; unconcerned by others noticing; received advice but professionals seen as powerless | Noticing patterns to flushes | Treatment and prostate cancer symptoms have affected sleep and sexual relationship; used to see self differently prior to diagnosis |
| | **Pp016** (78, BB, unknown, unknown) | Frequent flushes; includes severe sweating, "like someone has thrown … water"; chest, neck and face affected; generating heat | Flushes unexpected; unaware of cause | Flushes as "horrible" and "disgusting" and feels like "dying"; affects others; powerlessness; future course uncertain | Perceived as unwell or "dying"; not wanting others to know, negative consequences; no professional advice | Noticing irregular flushes | Uncertainty about prostate cancer diagnosis, thoughts about survival and others with cancer; change in self following diagnosis |
| | **Pp017** (45, BB, metastatic, other) | Sudden; includes "intense" sweating; intense sweats last 5mins, other sweats 1-2mins; head, face and neck affected initially and then spreads to body | Flushes expected, some "shock" when they began; aware of cause; unawareness of treatment for flushes | Interference with life; "uncomfortable" and embarrassing; concentration and mood affected; reduced strength and fatigue; affects others; future course uncertain; powerlessness-tolerance; acceptance; adjustment over time | Not wanting others to know; embarrassment; perceived as someone who has "let himself go", is ill or has something "wrong" with him; supportive wife; no advice, professionals limited | Noticing irregular flushes | Change in self following diagnosis, physical fitness reduced |

**NB. Men with concurrent high HFRS problem-ratings and high illness threat scores are highlighted in grey; WB refers to white British and BB refers to black British**

**Continuation of fig. 3.4**

| | | Thematic category | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | **Emotional reactions** | **General cognitive self-perceptions** | **HF/NS triggers, maintainers or alleviators** | **Management of HF/NS** | | | | **Sources of support** |
| | | | | | **Behavioural strategies** | **Cognitive strategies** | **Limitations** | **No or few strategies** | |
| **Participant** (age, ethnicity, cancer stage, hormone treatment type) | **Pp010** (51, WB, localised, androgen withdrawal) | Frustration; annoyance | Perceived reduction functionality and efficiency; belief in control over own body | Flushes occur "everywhere"; no specific triggers but tendency to occur with stress; worse after injection | Practical strategies: clothing/bedding removal, seeking fresh air or coolness; pausing activities to allow flush to pass; reluctance to cut out alcohol; not help-seeking | Trying to relax until flushes pass | Alternating between extremes | Belief that no strategies are used | Supportive wife; no interest in groups or self-help, unless advice is proven; preference for medication that does not interfere |
| | **Pp016** (78, BB, unknown, unknown) | Shame; fear related to confusion about flushes | Perceived reduced in daily activities and other physical problems also impacting on this | Flushes occur without pattern; no specific triggers but tendency to occur at "bedtime" | Practical strategies: wiping sweat, clothing removal, having a hot drink/ water or going to bed; sitting and waiting for flush to pass; help-seeking; reluctance to explain to others | - | Inability to fall asleep when retreating to bed because of "noisy" neighbours | - | Interest in treatment; preference for medication; no interest in talking about what could help |
| | **Pp017** (45, BB, metastatic, other) | Anxiety | Perceived decline in physical fitness and capabilities | Flushes "come when they come"; no specific triggers but may be influenced by ambient temperature or exercise; less frequent after injection | Practical strategies: using a fan, seeking coolness, drinking water, clothing removal or wearing lighter clothes; disguising flushes from others; social avoidance; calculating time-frames for activity; help-seeking | - | Strategies as imprecise and flushes uncontrollable | - | Supportive wife; attempted herbal remedies; interest in treatments that cause physical change without interference; no interest in self-help |
| | | | | | | | | | |

**NB. Men with concurrent high HFRS problem-ratings and high illness threat scores are highlighted in grey; WB refers to white British and BB refers to black British**

**Figure 3.5: Chart of thematic entries for men with low HFRS problem-ratings**

| | | Characteristics of HF/NS | Awareness and knowledge | Cognitions about HF/NS: | | | Cognitions about prostate cancer |
|---|---|---|---|---|---|---|---|
| | | | | Self | Others | General | |
| **Participant** (age, ethnicity, cancer stage, hormone treatment type) | **Pp001** (67, WB, metastatic, other) | Lasts2- 5mins, described as brief; feeling "hot" | Flushes expected; aware of cause; unaware of treatments for flushes | Adjustment; flushes as minor and a mixture of funny and irritating; powerlessness-acceptance; other side effects worse | Others don't usually notice; might be perceived as contagious or someone to pity; women joke, some "callous"; wife not completely sympathetic; received professional advice | Noticing irregularities and patterns; flushes as useful, able to empathise with women | Sleep affected by urinary urgency caused by prostate cancer |
| | **Pp021** (71, WB, metastatic, androgen withdrawal) | Initially infrequent, every 2-3days and lasted 15-20secs; currently 3 flushes per day; forehead and neck affected; no night sweats | Flushes expected , "pre-warned" and mentally prepare; aware of cause; unaware of treatments for flushes | Adjustment; flushes as not severe or distressing, but "uncomfortable" and humorous; lucky; able to cope; future course uncertain; others affected; limited changes in mood; "placid" predisposition; powerlessness-acceptance | Others don't usually notice, react with humour if they do; no effect on "how other people see me"; might be looked at "strangely" because people "do not understand what it is"; learned from wife; health professionals limited | Flushes as potentially useful for weight-loss and understanding what women's experiences; noticing irregularities in flushes | Sleep affected by urinary urgency caused by prostate cancer; more positive attitude since diagnosis; learning from others with cancer who survived the disease |
| | **Pp024** (65, WE, metastatic, androgen withdrawal) | Delayed onset; Lasts less than 2-3mins; includes feeling "hot" sweating on forehead and upper chest only; "breathlessness"; | Flushes expected; aware of cause, detailed biological account; unaware of treatments for flushes | Adjustment; flushes as a "nuisance" , minor compared to others and easy compared to other side effects; "no use worrying about things you cannot control"; influenced by past experiences; powerlessness-acceptance; perceived change in self due to hormone treatment – slower, tiredness, lack of energy, muscle loss, turning into "woman"; resistance to changes in life due to flushes; sleep not too badly affected; heat as enjoyable in past | Flushes as not noticeable; unconcerned by others noticing; sympathetic wife in some ways – dismissive at times; wife is affected by flushes; possible seen as "nuisance" by wife | - | Woken at night by urinary urgency; physical tiredness as side effect of prostate cancer treatments; physical changes – reduction in height |
| | | | | | | | |

**NB. WB refers to white British and WE refers to white English**

## Continuation of fig. 3.5

| Participant (age, ethnicity, cancer stage, hormone treatment type) | Thematic category | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Emotional reactions | General cognitive self-perceptions | HF/NS triggers, maintainers or alleviators | Management of HF/NS | | | | Sources of support for HF/NS |
| | | | | Behavioural strategies | Cognitive strategies | Limitations | No or few strategies | |
| **Pp001** (67, WB, metastatic, other) | Annoyance; humour | Age as cause for some physical decline | Less severe over time; worse after injection; no specific triggers identified but tendency to occur after hot drinks, when indoors and inactive and in evenings | Practical strategies: drinking water, clothing removal or wearing thinner clothing; explaining to others if necessary | - | Feeling "too hot or too cold" | - | Preference for medication; no interest in complementary treatments; interest in finding out about other men's experiences |
| **Pp021** (71, WB, metastatic, androgen withdrawal) | Humour | - | More severe over time; some triggers identified: worse in the evenings and affected by ambient temperature | Practical strategies: wiping self or seeking coolness; explaining to others; sitting and waiting for flushes to pass; flushes perceived as not severe enough to seek help | Ignoring flushes and remaining "cool, calm and collected" | - | - | Help from wife and drawing on her experiences; no interest in group or self-help |
| **Pp024** (65, WE, metastatic, androgen withdrawal) | Surprise; hope | Belief in mind over matter | Frequency increasing over time; some triggers identified: used to occur during day and during sporting activity when using increased pace, now anytime; worse symptoms at night, possibly due to bedding; no identified pattern relating to duration between injections | Practical strategies: clothing removal, seeking coolness, clothing choice; stop/sit and wait for flush to pass; breathing deeply; explaining to others, "openness is by far the best"; no help-seeking for flushes, "don't feel I need to", only if they got worse; reluctance to change bedding materials | Slowing down and focussing the mind | Difficulties deciding on clothing choice – not wanting to get too hot/cold. | Belief that few strategies are used | Interest in self-help for future management of flushes if necessary; belief that "I will manage it mentally" |

**NB. WB refers to white British and WE refers to white English**

General cognitions about HF/NS included noticing irregularities for men with high problem-ratings/illness threat and those with low problem-ratings. Beliefs about the helpful consequences of flushes were also held by men with low problem-ratings.

*Awareness and knowledge about HF/NS*

Awareness and knowledge of flushes across men from both groups was similar; all men had little awareness of treatments for flushes, most were expecting to have flushes and most were aware of their cause. One man with a high problem-ratings/illness threat (Pp016) did not expect his flushes nor understand their origin and, among other men with high problem-ratings/illness threat, there was mention of unpreparedness for flushes when they arrived, whereby this was associated with HF/NS characteristics and perceived severity.

*Emotional Reactions to HF/NS*

Emotional reactions to flushes included frustration, annoyance, shame and anxiety for both groups; annoyance was also an emotional reaction reported by men with low problem-ratings, however these men also reported reacting with humour, surprise and hope.

*HF/NS triggers, maintainers or alleviators*

Triggers, maintainers or alleviators for HF/NS were identified by men from both groups; men described flushes that occurred without a clearly identifiable pattern, but were able to provide some possible triggers and influences.

*Management of HF/NS*

Men from both groups engaged in behavioural strategies to manage their flushes that included practical cooling strategies. Men with low-problem ratings described explaining and disclosing flushes to others as a management strategy and chose not to help-seek, whereas those with high problem-ratings/illness threat gave accounts of management strategies that included help-seeking as well as social withdrawal and/or reluctance to manage flushes by explaining them to others. Among both groups,

cognitive strategies included attempts to calm the mind, limitations to management strategies reported were reported and no or few strategies were thought to be used.

Interest in support with flushes was sought by men from both groups. Men with high problem-ratings/illness threat expressed exclusive preference for pharmacological interventions that would not interfere with their hormone treatment and those with low-problem ratings expressed interest in pharmacological treatment or described other sources of support or interest in other interventions.

*Cognitions about prostate cancer and general cognitive self-perceptions*

Cognitions about prostate cancer included reports of symptoms and side-effects caused by prostate cancer and radical treatments and beliefs about changes in self-perceptions for both groups. Men with high problem-ratings/illness threat held beliefs that changes in themselves were declines in capabilities and those with low problem-ratings held beliefs that changes related to physical characteristics or changes in attitudes to life. Among those with high problem-ratings/illness threat, beliefs about declining abilities also appeared within the thematic category describing general cognitive self-perceptions; those with low problem-ratings had general cognitive self-perceptions that aimed to explain or cope with perceived changes.

### *3.4 Relationship between thematic categories and ethnicity*

Case analyses for the four black British men in the entire sample were conducted across the nine thematic categories; figure 3.6 displays a chart for these men. Three of these men had high HFRS problem-ratings and/or high illness threat (rows in fig. 3.6 are highlighted to indicate this). Due to missing information, trends associated with participant characteristics are unclear; only one man was aged younger than the average age of the entire sample, information regarding cancer stage was held for only one man and hormone treatment types were variable among the three men for whom this information was held. Dimensions of themes common among black British men are described.

Black British men described intense sweating as a common characteristic of HF/NS. They tended to have an awareness of the cause for flushes but were not always expecting them, which was associated with subsequent fear at the onset of flushes.

In terms of cognitions about HF/NS, flushes were perceived as embarrassing or shameful for most of these men; this was linked to unfavourable perceptions by others, negative consequences of others being aware of flushes and behavioural strategies such as social avoidance and disguising flushes or not explaining their incidence. It was common for the future course of flushes to be unclear for these men and for powerlessness over flushes to be linked to tolerance and acceptance. Professional advice about how to manage flushes was not received and/or was seen as limited by these men; one man did receive treatment for flushes but found that his flushes remained. Noticing irregularities or patterns to flushes were common general HF/NS cognitions.

Anxiety, shame and annoyance were emotional reactions described by black British men; happiness was linked to awareness of reductions in flushes or unexpected non-occurrences.

As with all men in the entire sample, possible triggers, maintainers and alleviators for HF/NS were identified, men engaged in behavioural strategies to manage flushes, cognitive strategies included attempts to relax and ignore flushes and men described limitations to management strategies. All men sought help for flushes but reluctance to explain flushes, disguising flushes and/or social avoidance were common behaviours. Men also held beliefs that few strategies were used to manage flushes.

It was common among black British men to express interest in treatment to manage flushes and to describe a preference for pharmacological management for flushes that was proven or did not interfere with hormone treatment; there was also some expression of interest in other interventions.

Prostate cancer cognitions included thoughts about changes in self-perceptions and decline in abilities following diagnosis and treatment and/ or consideration of future survival with the disease. General cognitive self-perceptions also encompassed declines in abilities or considerations about comorbid problems.

## Figure 3.6: Chart of thematic entries for black British men

| |
|---|
| High HFRS problem-rating and high illness threat score |
| High HFRS problem-rating |
| High illness threat score |

| Participant (age, cancer stage, hormone treatment type) | Characteristics of HF/NS | Awareness and knowledge | Cognitions about HF/NS: | | | Prostate cancer cognitions |
|---|---|---|---|---|---|---|
| | | | Self | Others | General | |
| **Pp016** (78, unknown, unknown) | Frequent flushes; includes severe sweating, "like someone has thrown… water"; chest, neck and face affected; generating heat | Flushes unexpected; unaware of cause | Flushes as "horrible" and "disgusting" and feels like "dying"; affects others; powerlessness; future course uncertain | Perceived as unwell or "dying"; not wanting others to know, negative consequences; no professional advice | Noticing irregular flushes | Uncertainty about prostate cancer diagnosis, thoughts about survival and others with cancer; change in self following diagnosis |
| **Pp017** (45, metastatic, other) | Sudden; includes "intense" sweating; intense sweats last 5mins, other sweats 1-2mins; head, face and neck affected initially and then spreads to body | Flushes expected, some "shock" when they began; aware of cause; unawareness of treatment for flushes | Interference with life; "uncomfortable" and embarrassing; concentration and mood affected; reduced strength and fatigue; affects others; future course uncertain; powerlessness-tolerance; acceptance; adjustment over time | Not wanting others to know; embarrassment; perceived as someone who has "let himself go", is ill or has something "wrong" with him; supportive wife; no advice, professionals limited | Noticing irregular flushes | Change in self following diagnosis, physical fitness reduced |
| **Pp020** (68, unknown, other) | Frequent night sweats, fewer flushes during day; includes "heavy" sweating and sensations of "tingling" and itching; gradual onset; lasts up to 5mins, usually 2mins | Flushes expected; aware of cause; unaware of treatment for flushes | Little interference except sleep disruption; perceived decline in abilities and masculinity affected; affects others; flushes as minor, cancer as greater concern; some idea of future course; powerlessness, tolerance, acceptance; attitudes influenced by upbringing | Sometimes others notice, but not often, unconcerned; wife sympathetic; professionals seen as limited | - | Physical effects of treatment, impotence and feeling less able to fulfil manly duties; considering survival and others who have died from cancer |
| **Pp032** (72, unknown, androgen withdrawal) | Flushes include feeling as though "body's not yours" and "something is working inside", "bad" sweating, heat in body and tightness/ shortness of breath; can feel flush "coming on"; sensations felt in abdomen and spreads to head, face and neck; frequent flushes at night in past, but reductions over time; less flushes during day | Flushes unexpected; aware of cause following help-seeking; unawareness of treatment for flushes except based on past treatment | Flushes as "uncomfortable" and embarrassing when unprepared; feeling unlike self during flush; disclosure to others about likelihood of sweating but not cause; affects mood, sleep and others; powerlessness-tolerance, acceptance; treatment as positive and essential; adjustment, interference with activities in past, but not now; future course uncertain, flushes for duration of treatment; impact of upbringing and comorbid illness | Others are curious and believe "something is wrong"; perceived as nervous or sick; others seek distance, including wife; not wanting others to ask questions or spread misinformation; embarrassment; women empathise; wife is sympathetic and understanding; professionals tried to help but limited | Noticing patterns to flushes; beliefs about flushes being worse than flushes reported by women | Religion as a means of battling cancer; considering life at present and the future course of the disease; no perceived change in self due to prostate cancer |
| | | | | | | |

## Continuation of fig. 3.6

| | |
|---|---|
| | High HFRS problem-rating and high illness threat score |
| | High HFRS problem-rating |
| | High illness threat score |

| | | Thematic category | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Emotional reactions | General cognitive self-perceptions | HF/NS triggers, maintainers or alleviators | Management of HF/NS | | | | Sources of support |
| | | | | | Behavioural strategies | Cognitive strategies | Limitations | No or few strategies | |
| **Participant** (age, cancer stage, hormone treatment type) | **Pp016** (78, unknown, unknown) | Shame; fear related to confusion about flushes | Perceived reduced in daily activities and other physical problems also impacting on this | Flushes occur without pattern; no specific triggers but tendency to occur at "bedtime" | Practical strategies: wiping sweat, clothing removal, having a hot drink/ water or going to bed; sitting and waiting for flush to pass; help-seeking; reluctance to explain to others | - | Inability to fall asleep when retreating to bed because of "noisy" neighbours | - | Interest in treatment; preference for medication; no interest in talking about what could help |
| | **Pp017** (45, metastatic, other) | Anxiety | Perceived decline in physical fitness and capabilities | Flushes "come when they come"; no specific triggers but may be influenced by ambient temperature or exercise; less frequent after injection | Practical strategies: using a fan, seeking coolness, drinking water, clothing removal or wearing lighter clothes; disguising flushes from others; social avoidance; calculating time-frames for activity; help-seeking | - | Strategies as imprecise and flushes uncontrollable | - | Supportive wife; attempted herbal remedies; interest in treatments that cause physical change without interference; no interest in self-help |
| | **Pp020** (68, unknown, other) | Annoyance | Perceived decline in capabilities and perceptions about possible impact of age | No specific triggers identified but flushes worse at night and affected by ambient temperature; possibly affected by spicy foods, alcohol and smoking | Information- and help-seeking; practical strategies: drinking water, clothing removal, wiping self, using a fan or seeking coolness; reluctance to cut out spicy foods but lifestyle changes; reluctance to explain to others; help-seeking; napping | - | Using a fan can lead to feeling cold | Belief that only one strategy is used | Interest in proven treatments with no other side-effects; no interest in groups; interest in self-help |
| | **Pp032** (72, unknown, androgen withdrawal) | Annoyance; fear related to confusion about flushes; happiness | Perceptions about impact of comorbid diabetes if not well controlled | Flushes as less frequent over time and less severe; some triggers identified: flushes affected by anxiety and stress and influenced by diabetic control | Help-seeking; practical strategies: using a fan, clothing removal and wiping self; maintaining healthy diet; withdraw until flushes settle; past social avoidance; explaining sweating to others but disguising cause, reluctance to explain to anyone but family | Pretending flushes are not there; trying not to stress, worry or get depressed; relax | Using fan does not stop sweating and can lead to feeling cold | - | Receipt of medication for flushes, unsuccessful; preference for medication but also interest in any proven treatment |

# Chapter 4: DISCUSSION

## *4.1 Summary of findings*

The primary objective of this study was to explore the experiences of HF/NS in men with prostate cancer who experience these symptoms as a side-effect of hormone treatment. The nature and effects of HF/NS experiences are under-researched in this population. It was possible, via a qualitative analysis of 19 men, to gain an understanding of the cognitive appraisals, socio-cultural meanings and behavioural reactions associated with HF/NS and to consider the way in which these factors interacted among these men. Given that men with a range of perceived HF/NS severities and cancer stages were recruited, it was also possible to address the secondary research aim relating to the types of appraisals, meanings and behaviours associated with flushes perceived as more or less problematic and with more threating illness representations.

### 4.1.1 Main qualitative findings

The findings of this study revealed that, on average, men had both frequent hot flushes and frequent night sweats but most men did not rate their flushes as severely problematic; average problem-ratings for HF/NS and perceived prostate cancer illness threat were mid-range. For most men these symptoms had been experienced for prolonged periods but most had not received or sought HF/NS treatments.

Qualitative analysis of men's experiences of HF/NS highlighted a complex interaction between the following nine superordinate themes: (a) the characteristics of HF/NS; (b) cognitions about HF/NS; (c) awareness and knowledge about HF/NS; (d) emotional reactions to HF/NS; (e) HF/NS triggers, maintainers and alleviators; (f) management of HF/NS; (g) sources of support for HF/NS; (h) cognitions about prostate cancer and (i) general cognitive self-perceptions. There was one centralised theme that was directly

and indirectly associated with the majority of themes, this was the theme labelled cognitions about HF/NS and consisted of HF/NS cognitions in relation to the self, to others and more generally. Of particular relevance were themes about HF/NS and the self associated with threats to masculinity, embarrassment, attitudinal accommodation to flushes (as influenced by perceived severity and factors associated with coming to terms with HF/NS) and perceived control over flushes. Themes about HF/NS and others associated with the salience of flushes and perceptions of others were also significant. Cognitions about flushes were influenced by somatic characteristics of HF/NS and in turn influenced HF/NS awareness and knowledge, emotional reactions to flushes, cognitive-behavioural management strategies and attitudes towards sources of support. Possible interactions between cognitions about HF/NS and socio-cultural factors, cognitions about prostate cancer and general cognitive self perceptions were also highlighted.

### 4.1.2 Problem-ratings and illness threat

High HF/NS problem-ratings co-occurred with high perceived illness threat among men in this study. Particular dimensions of themes were associated with men with higher HF/NS problem-ratings (and higher illness threat) and men with lower HF/NS problem-ratings. For example, men with higher problem-ratings described flushes that were "heavy" with excessive sweating, had an uncertain or negative future with a negative impact on them, were noticeable and led to unfavourable perceptions by other and were associated with frustration, annoyance, shame and anxiety. This differed from men with low problem-ratings who saw flushes as "mild" with minimal sweating, as having minimal impact on life, as being something to accept and adjust to, as either being unnoticeable or being noticeable but with little change in other's perceptions of them and as annoying but also humorous with some useful consequences. Themes in which differences were highlighted included HF/NS characteristics, cognitions about HF/NS, cognitions about prostate cancer, general cognitive self-perceptions, emotional reactions to HF/NS and behavioural HF/NS management strategies.

The extent to which demographic variables influenced scores was not statistically examined given the qualitative nature of this study and the small sample size. However some trends were apparent; high HF/NS problem-ratings/illness threat was common to younger men within the sample and black British men and low HF/NS problem-ratings were common to white British/English men with metastatic prostate cancer.

### 4.1.3 Socio-cultural differences

Unfortunately due to the relatively small proportion of black British men recruited to the study, it was not possible to maximise this demographic variable in order to conduct separate thematic analyses of HF/NS experiences among these men and consider any similarities or differences in the dominant themes for men from different ethnic backgrounds. This limited black British sampling frame minimised the likelihood of achieving thematic saturation for an analysis of phenomenal variation in HF/NS; thus, the final research aim was not addressed. However it was possible, via case analysis of framework charts, to consider similarities among black British men across the thematic categories generated for the entire sample in order to establish any key themes for this group of men.

Overall, themes and dimensions of themes were similar to that of the majority sample. Three of the four black British men considered had higher HF/NS problem-ratings and/or illness threat scores, thus the themes associated with men with these illness characteristics also applied to most black British men. In addition to this, case analyses revealed that black British men had flush characteristics associated with intense flushes and experienced embarrassment and/or shame in relation to flushes; emotional reactions included anxiety, annoyance and shame. HF/NS experiences were linked to unfavourable perceptions by others and perceived undesirable consequences, should others notice flushes, as well as behavioural strategies such as the non-disclosure and/or disguising of flushes and social avoidance. Embarrassment about noticeable flushes and a desire for flushes to go unnoticed was also reported in the majority sample; however, these themes were reported by few men and were

associated with men not wanting to be treated differently by others or pitied. There were also men in the majority sample were unconcerned by others noticing their flushes. Professional advice about how to manage flushes was seen as limited and/or was not received by black British men, although all sought help for their flushes; this was similar to findings in the majority sample, as were findings related to the perceived future course of flushes and perceived powerlessness over flushes.

## *4.2 Methodological considerations*

### 4.2.1 The benefits of qualitative research

It was possible to identify a range of cognitive-behavioural experiences associated with HF/NS in men with prostate cancer using a qualitative methodology. Qualitative, semi-structured interviews undertaken within this study allowed the generation of novel themes alongside the exploration of a priori topics derived from existing research about HF/NS in men and in other populations, thus HF/NS were explored in a wide-ranging and inclusive fashion. The use of such techniques is encouraged in health research, particularly when studies aim to provide a basis for quantitative investigation of under-researched topics (Pope & Mays, 1995); for example qualitative interviews were undertaken by Rendall *et al.* (2008) as a part of a mixed-methods design in which interviews providing a preliminary investigation of HF/NS cognitions were used to develop a measure that was subsequently adapted into the HFBS following factor analysis. It was hoped that the findings of this study could be used to inform future qualitative investigation of HF/NS in men with prostate cancer. Thus the extensive features of qualitative interviewing were essential; relevant information may have been overlooked had a solely quantitative approach been undertaken, particularly given that men's experiences of HF/NS are under-researched and common characteristics of cognitions, meanings and behaviours associated with HF/NS in this population are less clear.

In addition to the general rationale for undertaking qualitative, semi-structured interviews, there were also benefits associated with the face-to-face interview format.

For example, men were able to ask questions and clarify any ambiguity or confusion arising from their questionnaires during the preliminary interview stage where completed questionnaires were collected. It was also possible for missing items to be identified and completed during this interview stage. In addition to this there were some men who had flushes within their interviews, which may have aided the accessibility of flush-related cognitions, particularly those related to being observed during a flush.

### 4.2.2 Study limitations and recruitment issues

Despite the benefits of using qualitative interviews, there were some limitations to this process. Interviews were lengthy and therefore both costly and time-consuming to participants, particularly those who had to travel greater distances, and to researchers. There were also recruitment issues related to the requirement that all interviews be conducted face-to-face, for example, one man was not recruited because he was unable to travel to either of the two interview sites (due to a physical impairment) and three men declined interview because they were reluctant to travel. It could therefore be argued that this study included a self-selected sample that may have attracted men more motivated or willing to attend interviews based on the extent to which their flushes were problematic. However, this was unlikely to be the case given that the sample included men with flushes that ranged from low to high problem-ratings; maximum variation sampling was undertaken to ensure that this was the case.

Although attempts were made to maximise demographic variation as well as phenomenal variation of flush problem-ratings, there were additional recruitment issues related to this.

*Recruitment of black British men*

Only four black British men were recruited to this study; the majority of the study sample included white British, English or Irish men. Thus there was a lack of variability

in the ethnicities of men within the study and the dominant themes identified may reflect the views of the majority ethnic group.

Reasons for the small proportion of black British men recruited are unclear; one possibility is a general lack of interest in the study by men from this population. Of the 44 men who expressed interest in the study, only 9 were black British men and of the 7 men who expressed interest in the study following thematic saturation, none were black British. When considering the 5 black British men who were initially interested in the study but were not recruited, 3 declined interview (2 of whom gave practical reasons for this, such as extended holidays abroad) and 2 were unreachable by phone despite repeated attempts to contact them. Thus, it is unclear whether these men lacked interest in the study or whether there were simply practical or personal reasons for non-recruitment.

Another possible reason for the limited recruitment of black British men relates to the recruitment methodology undertaken within this study; men were recruited from hospital groups and services (predominantly via posters and referrals from clinicians). Similar recruitment methods have been undertaken in other qualitative studies of men with prostate cancer and underrepresentation of minority ethnic groups have also occurred (Chapple & Ziebland, 2002; Grunfeld *et al.*, 2012). According to Nanton and Dale (2011), African-Caribbean men are underrepresented in the UK's qualitative cancer research and the authors describe the employment of community-based recruitment strategies in order to gain access to this "hard to reach" or "seldom heard" (p. 63) population. Similarly, in Rajbabu *et al.*'s (2007) study of knowledge and beliefs about prostate cancer in a non-clinical sample of men, additional recruitment strategies were enlisted to encourage study participation among men from black and minority ethnic groups. The extent of recruitment difficulties involving men from African and Caribbean descent was unanticipated and this study may have been improved with the addition of recruitment methods which specifically targeted men from this population. For example attempts could have been made to recruit men via local community agencies such as churches or community groups, in particular the UK prostate cancer charity may have been a valuable recruitment source and has a division for African and Caribbean communities that organises community events.

Adaptations such as these may have aided recruitment and allowed the final research question to be addressed.

*Recruitment of younger men*

Recruitment of men from younger age groups was also limited in this study; only two men were in their 40s-50s and one reason for this was related to the availability of younger men within the sampling frame. Age is a risk factor for prostate cancer, whereby higher rates occur in older men and the disease rarely appears in men before the age of 40 (Bostwick *et al.*, 2004). There were therefore fewer younger men to recruit and this demographic variable was reflected but minimised. It is of note that had this theme been maximised, themes generated in this study may have been different. For example, older men in this study commented on a reduction in their daily activities due to their age as well HF/NS and prostate cancer; such age-related general cognitive self-perceptions affected cognitions about flushes.

Although the demographic variables of ethnicity and age were minimised in this sample, this meant that recruitment could continue with men who were homogenous in terms of these characteristics and fewer sampling units were required to ensure the credibility and validity of study findings (Sandelowski, 1995).

### 4.2.3 Reliability and validity

*Respondent Validation*

Although all men gave accounts of their HF/NS during interviews, no form of respondent validation was enlisted to verify derived interpretations. This is a popular component of qualitative research (Barbour, 2001) and can be useful for the refinement of research findings and interpretations (Barbour, 2001; Pope & Mays, 1995). Although, respondent validation was not used in this study, a study aim was to ultimately devise an index of cognitive-behavioural experiences, which could be used

to develop a preliminary measure of HF/NS in men with prostate cancer. Thus, the findings of this study represent the beginning of a series of stages that will involve further analysis and refinement of men's cognitive-behavioural experiences via validation in samples of men with prostate cancer.

*Assessments of validity and reliability*

The reliability of coded items from interview transcripts was not assessed using statistical calculations of interpretive convergence as part of this study for the reasons outlined previously (see Methodology). Instead there was a focus on group discussions to assess the reflectiveness of codes and attempts were made to ensure accessibility to analytical processes as specified by the requirements of the framework method and to adhere to checklists that specify criteria for reliable and valid qualitative research as described below.

According to Yardley's (2000) criteria for 'good qualitative research' (p.219) in health research, there are 4 key dimensions on which qualitative studies can be assessed. These include: (a) sensitivity to context; (b) commitment and rigour; (c) transparency and coherence and (d) impact and importance. The ways in which this study fulfilled criteria are outlined:

*Sensitivity to context* refers to researchers having an awareness of the various aspects of the qualitative process including the theoretical background to a research topic, relevant literature and previous empirical findings, issues relating to a study's socio-cultural setting, participant's perspectives and ethical issues. In this study, previous theory and empirical findings were thoroughly explored and a reflexive stance was taken that allowed socio-cultural contextual issues to be considered.

Dimensions relating to *commitment, rigour, transparency and coherence* all describe qualities of data collection, analysis and reporting that should be sought in qualitative research. *Commitment* was ensured in this study initially during the familiarisation stage of the framework method but also throughout all stages. This involved

immersion in audio-recordings, interview transcripts, coding, charts and research memos. *Rigour* was demonstrated in both the breadth and depth of the sample, whereby a purposeful sample of men with a variety of HF/NS experiences was selected and the sample size was sufficient in order to reach informational redundancy. Unfortunately it was not possible to ensure demographic variety in the sample in terms of ethnicity, which prevented separate thematic analysis based on this factor but possible reasons for this have been outlined and this study limitation did not prevent data saturation when thematic analysis was conducted across all men. The rigour of this study was also strengthened by undertaking various verification strategies as reported by Morse *et al.* (2002); these included: ensuring coherence between study aims and the methodology undertaken (methodological coherence); the selection of an appropriate sample; collecting and analysing data concurrently and thinking theoretically, allowing emergent ideas to be reconfirmed in new data.

*Transparency and coherence* were requirements of the framework method and attempts were made to ensure that all stages of the qualitative process were clearly described. Interpretive maps, charts and extracts from interview transcripts were made visible to allow readers to clearly identify suggested interpretations, associations and patterns within the data; a sub-sample of interview transcripts are also available to readers (appendices J-L). Transparency was also achieved via reflexivity.

Reflexivity is defined as attentiveness to 'the context of knowledge development … at every step of the research process' (Malterud, 2001, p.484). Maintenance of reflexivity acts as a means of addressing researcher bias by considering the effects of researchers on the research process and making any potential effects salient. For example, Malterud (2001) describes the effects of researcher's preconceptions, based on factors such as personal and professional experiences, beliefs and motivations, and the need to establish metapositions in order to create distance between the researcher and study settings so that competing conclusions or interpretations can be made. In this study, all interviews were audio-recorded and transcribed verbatim in order to both create distance and ensure that this information was available for others to make interpretations. It is possible that study findings could have been different if the primary researcher conducting interviews had different personal characteristics,

including gender, ethnicity, clinical role and research interests. For example, there were men in the study who may have had difficulties expressing vulnerabilities such as threats to masculinity to another male or there may have been black British men who identified with the common ethnic background of the primary researcher and therefore felt able to share spiritual views based on perceived ideas of mutuality or shared cultural experiences. The primary researcher in this study was a trainee clinical psychologist with an interest in mood disorders and health psychology, thus there may have been some motivation to identify relationships associated with clinical issues, such as emotional disturbance, and patterns that were consistent with existing models of illness and symptom perceptions. These possible influences and motivations were highlighted throughout the research process and attempts were made to seek advice and explore alternative interpretations of findings in group discussions with research supervisors and two reviewers as well as in monthly meetings with one research supervisor.

*Impact and importance* refers to the extent to which findings enrich understanding and can be utilised by the community for whom it was intended or deemed useful based on study objectives. The relevance and implications of findings for this study are outlined below.

### *4.3 Comparison with other studies and implications for clinical practice*

This study is one of the few that have explored the experiences of men with prostate cancer specifically in relation to HF/NS. Although similar investigations of the themes associated with this treatment side-effect have been conducted in previous studies, this exploration is novel in that generated themes have been elaborated and considered in terms of the ways in which they interact with one another and with flushes of differing perceived severities.

The nine thematic categories identified in this study bear some resemblance to themes or accounts of experiences associated with HF/NS that have been reported by previous researchers investigating men with prostate cancer (Coyne *et al.*, 2006; Chapple &

Ziebland, 2002; Grunfeld *et al.*, 2012; Nanton & Dale, 2011), healthy women (Hunter *et al.*, 2011; Rendall *et al.*, 2008) and women with breast cancer (Hunter, Coventry, Mendes *et al.*, 2009). However novel themes were also identified; interactions between themes were largely in line with expectations based on models of HF/NS and illness, with some deviations associated with novel themes.

### 4.3.1 Themes and interactions common to other studies

Commonalities between themes generated in this study and those identified in past studies were identified in several categories; possible interactions between certain dimensions of themes and HF/NS problem-ratings were also identified. The descriptions below relate to the similarities or interactions identified within the following themes: cognitions about HF/NS; management of HF/NS; emotional reactions to HF/NS; sources of support for HF/NS and awareness and knowledge about HF/NS.

*Cognitions about HF/NS: interference as a component of coming to terms with flushes*

There were men who reported that flushes interrupted sleep and relaxation as well as concentration, work efficiency, mood and sexual activities; there were men for whom flushes directly affected these factors and men who felt that flush-related sleep disturbance was associated with subsequent effects on other activities, e.g. concentration. The impact of flushes on daily life, sleep and mood in men were also reported by Grunfeld *et al.* (2012), whereby sleep disturbance related to night sweats was also implicated in daytime fatigue. The findings relating to sleep disturbance in this study are also similar to reports from studies of healthy women (Rendall *et al.* 2008) and women with breast cancer (Hunter, Coventry, Mendes *et al.*, 2009). However, the direct effect of flushes on daily activities seems to be a particular issue for men with prostate cancer.

These findings suggest that QoL for men with prostate cancer can be negatively affected both directly and indirectly by flushes and that these effects are in some ways similar to those reported by women. In this study, the extent to which men were able to accommodate to flushes was influenced by beliefs about how life-interfering flushes were (as a component of judgements about flush severity) and how much they affected cognitive processes and physical activities. Thus, beliefs that flushes led to cognitive-behavioural changes and caused interference played a role in the extent to which men were able to come to terms with their flushes. Men's attitudes towards the potential effects of flushes on their QoL are therefore significant and could be a target for psychological intervention.

*Cognitions about HF/NS: perceived control*

Powerlessness over HF/NS was a common theme among men in this study suggesting that men felt they had little control over their flushes. Grunfeld *et al.*, (2012) also identified themes associated with a lack of control over flushes in men with prostate cancer. Beliefs about perceived control over flushes have also been reported by women with breast cancer (Hunter, Coventry, Mendes *et al.*, 2009), whereby women reported feelings of being out of control; the authors in this study theorised that struggle for control was likely associated with increased frustration and distress. In this study, men's powerlessness was associated with acceptance and/or tolerance of HF/NS. It could be postulated that tolerance of flushes may have been associated with increased frustration and that such feelings may have been related to men engaging in a losing battle for control and feeling forced to endure their symptoms. Conversely, acceptance of HF/NS was closely associated with adjustment and coping and one could argue that these men disengaged from a battle for control and instead made adaptations to their lives to include flushes and incorporate them as part of life. Interventions that encourage acceptance and adaptation to emotional and health problems currently exist, such as mindfulness-based cognitive therapy (Segal *et al.*, 2002) and acceptance and commitment therapy (Hayes *et al.*, 2003), and components have been successfully used in interventions to help women cope with HF/NS (Ayers *et*

*al.* 2012; Mann *et al.*, 2012); this could also be relevant in the management of HF/NS in men with prostate cancer.

*Cognitions about HF/NS: impact on masculinity*

The impact of HF/NS on masculinity was a theme that has not been identified specifically in relation to HF/NS in previous research; Chapple and Ziebland (2002) found that men with prostate cancer reported reductions in their sense of masculinity as a result of the effects of a number of side-effects of hormone treatment, which included but was not exclusive to HF/NS, on their social constructions of a male identity. For example, there were men in the study who believed that the side-effects of hormone treatment had resulted in physical and emotional changes that resembled those seen in women and that side-effects had negatively influenced their interest in sex, energy levels, enthusiasm for work, competiveness and sense of control over their bodies (Chapple & Ziebland, 2002). In the current study, similar beliefs associated with reductions in a sense of masculinity were identified; men reported feeling that HF/NS were "unmanly" symptoms that were commonly associated with menopausal women and some joked about turning into or behaving like women, whereby they referred to mood changes associated with both HF/NS and hormone treatment. There were also men for whom other side effects such as reduced sexual desire (sometimes due to flushes) and impotence also impacted on their sense of masculinity. Thus HF/NS both alone and in conjunction with other side-effects were perceived as emasculating. Some men appeared to cope with this threat to masculinity using humour, suggesting that they were able to retain a sense of masculinity, possibly by reframing the traditional ideas of masculinity applied to them as suggested by Oliffe (2006). For other men, it is possible that some management strategies associated with HF/NS were also associated with attempts to cope with this emasculated social perception, for example there were men who were reluctant to disclose flushes, attempted to disguise them and/or were socially avoidant; such interpersonal coping strategies have been reported by men with prostate cancer in response to bodily feminisation (Navon & Morag, 2003). An awareness of the way in which men construct their male identity and

the impact of HF/NS on this may be necessary in any intervention that targets HF/NS in this population. Cognitions, behaviours and emotions associated with threats to masculinity could be targets for intervention.

*Cognitions about HF/NS: interactions between cognitions and reporting*

The role of negative affectivity in symptom reporting has been demonstrated in both men and women (Watson & Pennebaker, 1989) and is suggested as a possible factor influencing HF/NS perception and reporting by Hunter and Mann (2010). As reported in studies exploring HF/NS in healthy women, negative or catastrophic appraisals are associated with perceptions of more problematic flushes (Reynolds, 1997, 2000) and a similar pattern in which negative thoughts, in the form of more threatening illness appraisals, result in increased reporting of negative outcomes is reported in men with prostate cancer (Green et al., 2002; Traeger *et al.*, 2009; Wallace, 2003). In this study, men with high HF/NS problem-ratings reported HF/NS experiences that differed from men with low HF/NS. For example, within the theme relating to HF/NS cognitions and the self, men endorsed subthemes that included impact on masculinity, undesirable changes in abilities and the self that were associated with flushes, powerlessness and uncertainty about the future course of the disease. Similarly within the theme about HF/NS cognitions and others men reported noticeable flushes and held views that unfavourable consequences were associated with such flushes as well as holding views that health professionals were unable to help. Thus, themes endorsing negative attitudes to HF/NS appeared to influence the reporting of problematic flushes for men in this study; this suggests that men displayed a similar interaction between negative affectivity, negative cognitions and symptom reporting as proposed in Hunter and Mann's cognitive-behavioural model of HF/NS (2010). This is a tentative finding that would need to be verified with quantitative investigation and could indicate the use of cognitive-behavioural interventions for men with HF/NS.

*Management of HF/NS*

Several behavioural strategies identified among men in this study were also identified in previous investigations of HF/NS. Practical behavioural strategies such as attempts to cool down as well as behaviours such as social avoidance and disclosure were all reported by men in this study. Grunfeld *et al.* (2012) identified similar management strategies in their study of men with prostate cancer and this is consistent with strategies that have been reported by women with breast cancer (Hunter, Coventry, Mendes *et al.*, 2009) and healthy women (Hunter *et al.*, 2011). There were some cognitive strategies that were categorised as positive behavioural reactions in studies of women, such as ignoring hot flushes (Hunter *et al.*, 2011; Hunter, Coventry, Mendes *et al.*, 2009). However, unlike other studies of HF/NS management strategies, a number of additional cognitive strategies were identified among men in this study such as externalising flushes, positive thinking and willing flushes away. Many men also reported help-seeking or information-seeking for HF/NS and most men described informing someone (a healthcare professional, close friend, family member or another individual) in order to seek help.

These findings differ from studies reporting that men with prostate cancer tend to do little to manage their flushes (Coyne *et al.*, 2006); however it is of note that men in this study also reported using no or few strategies, despite giving accounts of techniques that they had used. The reasons for this were associated with men's minimisation of their management strategies; most men had little confidence in the strategies they were using due to perceptions of powerlessness over flushes.

Thus, men seemed to have a repertoire of strategies to manage HF/NS but their perceptions of self-efficacy and powerlessness over HF/NS, in addition to perceived limitations of strategies, affected the likelihood of having confidence in strategies and potentially engaging in them. This suggests that perceived control over flushes was a pervasive theme that influenced behaviour and could therefore be a powerful target for interventions to manage HF/NS.

*Emotional reactions to HF/NS*

As reported by Grunfeld *et al.* (2012), emotional reactions to HF/NS included annoyance in response to HF/NS; men in this study also reported experiencing shame in relation to other's noticing flushes, aggression and irritability as a consequence of flushes and fear or surprise associated with the initial onset of flushes, whereby similar findings were reported by Grunfeld *et al.*, (2012). Shame and/or embarrassment has been associated with concern's about perceptions by others in men with prostate cancer (Grunfeld *et al.*, 2012), healthy women (Rendall *et al.*, 2008) and women with breast cancer (Hunter, Coventry, Mendes *et al.*, 2009), whereby such emotions and associated cognitions have been shown to influence behavioural reactions to flushes. In this study, a similar process took place; there were men who expressed a reluctance to disclose flushes or who attempted to disguise them due to embarrassment or feelings of discomfort or shame. It is of note that men in this study reported a range of positive as well as negative emotions in relation to HF/NS, whereby emotions such as happiness and humour, relief, hope and gratefulness were described in relation to multiple factors including reactions to flushes and treatment. Exploration of emotional reactions therefore yields different cognitions and meanings and men in this sample varied in their reactions; this study has identified some possible meanings that could be relevant targets for intervention.

*Sources of support for HF/NS*

Informal sources of support for HF/NS were identified by men in this study; there were men who described helpful encounters with other men in waiting rooms and others who identified compassionate partners and pets as sources of support. Similar descriptions of support being sought from sources other than those delivered in formal settings have been reported in men with prostate cancer, whereby men have described receiving support from family members, church groups, local community groups and informal PCSGs (Nanton & Dale, 2011). It could be argued that enlisting help from sources other than medical professions can be empowering in that any

perceived imbalances of power between healthcare professionals and patients can be controlled by patients; questions can be asked and advice and information may be sought with greater freedom. In this study, some men were involved in an informal PCSG that was run by patients and others described seeking advice and information from other men with prostate cancer. The use of informal sources of support can therefore be complementary to formal treatments.

*Awareness and knowledge*

Most of the men in this study reported a lack of awareness of HF/NS treatments, with many believing that there was nothing that could be done about their flushes. This influenced men's perceptions of healthcare professionals in that although men believed healthcare professionals to be helpful, they also saw this help as limited. Awareness and knowledge of flushes in Grunfeld *et al.*'s (2012) study was related to the cause of flushes, whereby men were unaware that hormone treatment was the reason for their flushes and experienced confusion and anxiety in relation to their symptoms as a result of this. In this study, there was a similar theme associated with awareness of the cause for flushes; most men were aware of the cause, although there were some who reported confusion and fears about flushes at their initial onset, whereby men varied in terms of whether or not they were prepared for and therefore expecting flushes. Some men reported being informed of flushes and others reported that they were not or had difficulties recalling this information; flushes with a delayed onset was related to this. These findings suggest that in practice, professionals may need to offer more information regarding HF/NS treatments, when not explicitly asked by men. They may also need to provide information about the side-effects associated with hormone treatments and give provide men with information about this that they can refer between consultations.

### 4.3.2 Novel themes influencing HF/NS experiences

In addition to identifying themes that have been described in previous studies, some novel themes also arose from this study, some of which were distinct from HF/NS experiences but all of which had some influence on men's experiences.

*Cognitions about prostate cancer*

Given that this is one of the few studies specifically exploring HF/NS in men with prostate cancer, it was unclear how prostate cancer appraisals (i.e. illness representations) would influence reports of HF/NS experiences. According to Hunter and Mann (2010), cognitive appraisals associated with the cause of flushes (i.e. menopause) in women are thought to influence the reporting of HF/NS and perceptions of the extent to which they are problematic. Previous research has indicated a correlation between negative beliefs about HF/NS and negative beliefs about the menopause and an association between more problematic HF/NS and negative cognitions about HF/NS (Rendall *et al.*, 2008).

Half of the men who reported high flush problem-ratings in this study also reported high illness threat, which suggests, that HF/NS experiences and cognitions relating to the cause for HF/NS, in this case, prostate cancer illness representations, may influence one another. No statistical analyses were performed due to the predominantly qualitative nature of this study and the small sample size, thus this finding lacks reliability and would need to be explored in future studies. However, examples of a possible interaction of this kind were reflected in the themes that were generated; prostate cancer cognitions were identified as a theme separate to HF/NS experiences but interacted with HF/NS experiences in various ways. For example, prostate cancer-related self-perceptions, in which men reported changes in themselves following diagnosis and treatment, were associated with the changes in themselves that had resulted due to HF/NS; there were men who felt that prostate cancer had led to a number of negative changes and these men also believed HF/NS also resulted in undesirable changes in themselves. Similarly, men described thoughts

about their likelihood of recovery from prostate cancer, such descriptions represent uncertainty associated with death, which is something that these men had no control over; this was parallel to men's reports of powerlessness over their HF/NS.

*General cognitive self-perceptions*

Themes associated with general perceptions about the self as distinct from those specifically associated with HF/NS were all categorised under one theme. This theme was unexpected and may have been influenced by the demographics of the sample; for example, there were men who reported a general decline in their capabilities and men who described comorbid physical illness, whereby some men attributed these changes to their age. The average age of men in the sample was 68.8 years and most were retired; factors associated with self-perceptions may have differed in a younger sample with fewer comorbid problems. This theme was an overarching theme and it is proposed that this may have affected men's HF/NS cognitions and their attitudes towards their flushes. It is possible that among men with experience of adjustment and acceptance (via experiences of comorbid problems or progressive decline in other capabilities), helpful attitudes and cognitions associated with these experiences could be applied to their HF/NS. This generalisation of learned coping was described by some men, whereby one man with diabetes and another with asthma spoke of the ways that these physical conditions had helped them to cope with their prostate cancer and HF/NS.

*Socio-cultural influences: the role of upbringing/ background*

There were men in this study who described experiences of dealing with adversity that had helped them to cope with their HF/NS by allowing them to adopt helpful perspectives and coping strategies. Some men gave accounts of personal experiences and others referred to observations or accounts they had heard through others. Thus, upbringing and background may have influenced accommodation to HF/NS, whereby

those men with experiences of adversity were able to come to terms with their symptoms. It is possible that socio-cultural factors may have played a role in this theme; based on reported educational levels, men were from a range of socio-economic backgrounds and some men who spoke of adversity referred to periods of being materially deprived in their lives. However, the extent of socio-cultural influences were unclear as there were also men who spoke of adversity related to events that were unrelated to socio-economic background, such as men who spoke of their experiences or their parent's experiences during wartimes.

*Socio-cultural influences: the role of ethnicity*

As outlined previously, it was not possible to consider thematic differences relating to ethnicity in the way that was proposed in initial study aims. However, an examination of the themes that were generated in this study among the four black British men was possible; some common dimensions of themes were identified among members of this population but differed from the majority sample. For example, themes of shame and/or embarrassment appeared among all but one of these men, whereby men expressed desires for their flushes to go unnoticed and noticeable flushes were associated with social consequences that were perceived as negative, such as people asking questions and spreading misinformation or being perceived as unwell or not normal. These consequences all seemed to relate to men's desires to protect information about their flushes and/or prostate cancer diagnosis. This concern about social evaluation was associated with behaviours such as social avoidance, non-disclosure and/or disguising of flushes. Perceptions of shame and stigma have been associated with general ill health, whereby these perceptions are associated with social constructions of ill-health (Strandmark, 2004). It is possible that social evaluative concerns among black British men may have been influenced by certain socio-cultural beliefs and meanings associated with illness and being perceived as unwell by others; there is research exploring the effects of perceptions of shame and stigma among black and minority ethnic groups in relation to mental ill-health (Harrison *et al.*, 1989; Morgan *et al.*, 2005) and this may also extend to general ill-health. Social evaluative

concerns also applied to other men within the study who expressed desires to conceal their flushes, however among the majority sample threats to masculinity were identified as the meaning that men associated with flushes rather than specific beliefs about being perceived as ill, unwell or not normal.

Lack of awareness about prostate cancer has been reported in black British men (Boyd *et al.*, 2001; Agho & Lewis, 2001; Rajbabu *et al.*, 2007). Nanton *et al.* (2009) reported that lack of awareness in their sample of black British men was linked to problems in healthcare professional-patient communication, whereby men tended not to inquire about their disease and reported that healthcare professionals had unhelpful communicative styles. In this study, like the majority of men, black British men varied in terms of being prepared for HF/NS but most were aware of their cause and it was common for men to view healthcare professionals as helpful but limited. Thus, most of these men were informed about aspects of their disease such as the potential side-effects of hormone treatment, which differs from Nanton *et al.*'s (2009) findings and from research literature suggesting that black British men lack awareness and knowledge about prostate cancer. Only one black British man had little knowledge about HF/NS and expressed uncertainty about his prostate cancer diagnosis.

It is also of note that of those men selected for consideration of high HF/NS problem-ratings and high illness threat scores, two black British men had high problem-ratings, whereby one of these men also reported high illness threat and one other black British man also reported high illness threat. Thus, problematic flushes and/or threatening illness representations among these men were high. However, given that such a small sample was considered, it is not possible to make inferences from quantitative measures and further exploration is required to assess HF/NS in black British men.

### 4.3.3 Comparisons with existing models of HF/NS

Several subthemes fell into the category labelled cognitions about HF/NS and other themes were strongly associated with it. The centralised role of this theme and its relationship with other themes is illustrated in figure 4.1. Experiences of HF/NS in

which cognitions about these symptoms are centralised is a pattern that corresponds with the way that appraisals about flushes were theorised in Hunter's (2003) cognitive model of menopausal hot flushes and suggests that the way men appraise their HF/NS is a key component of the entire flush experience.

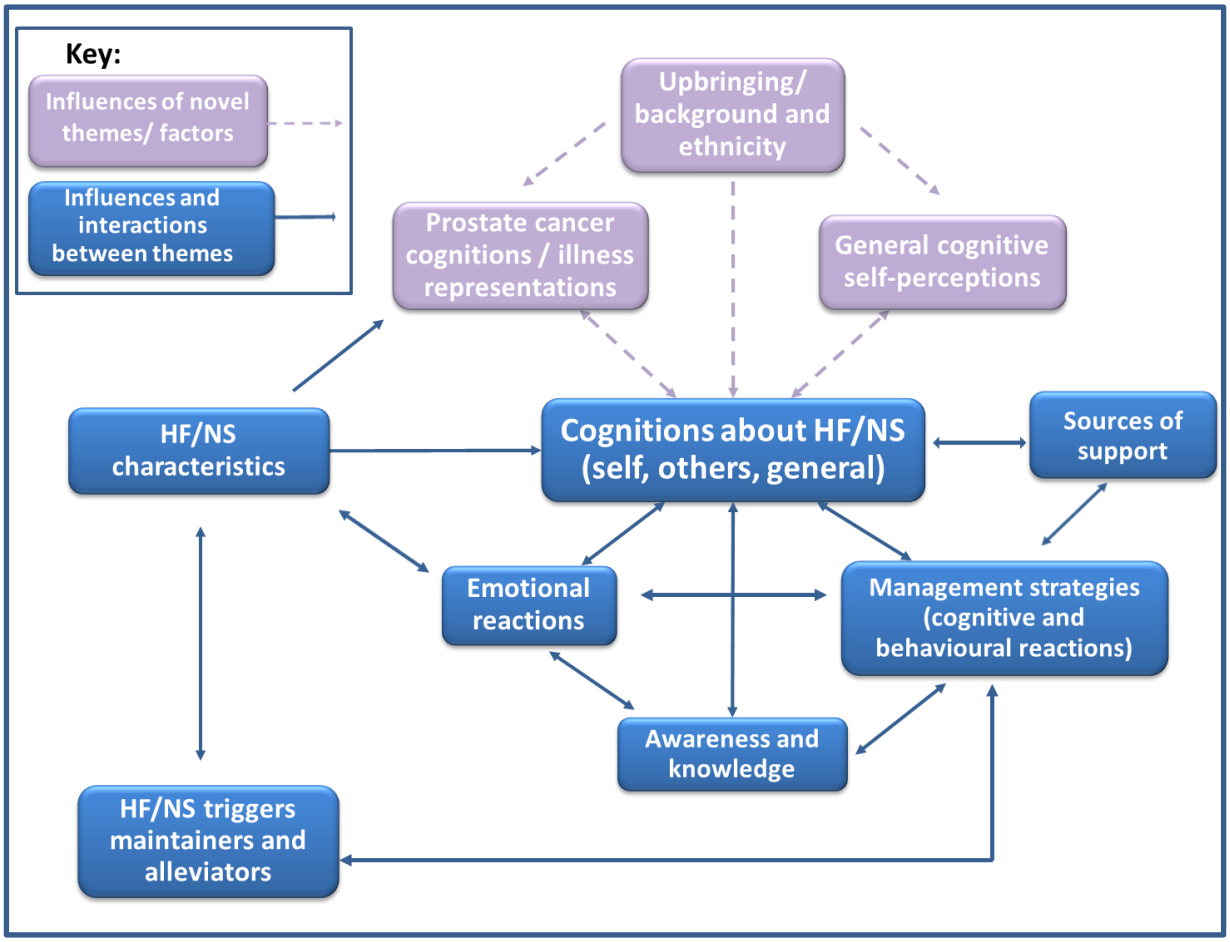


**Figure 4.1: A model of the interacting themes and influences generated from men's HF/NS experiences in this study (themes/influences novel to this study are highlighted)**

The HF/NS experiences reported by men in this study fell into thematic categories that were similar to some of the factors identified in both Hunter and Mann's (2010) cognitive-behavioural model of HF/NF and Hunter's (2003) model of menopausal HF/NS. For example, mood, behavioural reactions to flushes and physical changes associated flushes are all components in both models and were all themes generated

from men's experiences in this study. The possible interactions between themes among men in this sample that have been described throughout this report and are illustrated in figure 4.1 is similar to Hunter's (2003) model; physical characteristics of flushes directly influenced HF/NS cognitions and there were two-way interactions between HF/NS cognitions and emotional reactions and cognitions and management strategies. In Hunter and Mann's (2010) model one-way interactions are illustrated from behavioural reactions to mood and to beliefs, however the men in this study reported emotional reactions and cognitions that influenced management strategies and some strategies influenced or targeted mood (e.g. attempts to relax) and cognitions.

The additional influences of cognitions (illness representations) about prostate cancer, general cognitive self-perceptions and socio-cultural influences (in the form of upbringing/background and ethnicity) on HF/NS cognitions are also demonstrated in figure 4.1; these novel influences are highlighted. This bears some resemblance to the Hunter's (2003) model of menopausal hot flushes, which also considers the role of social and cultural influences in the development of cognitions about flushes, and to Hunter and Mann's (2010) cognitive-behavioural model of HF/NS, which considers the role of beliefs about the cause for flushes and its interaction with HF/NS cognitions.

Thus it seems that models of HF/NS experiences in women have significant similarities with the interactions of themes identified among the men in this study. If these themes and interactions are found to occur more widely among men with prostate cancer who experience HF/NS then this could help to inform cognitive-behavioural inventions for flushes among these men. Such treatments, found to be effective for managing HF/NS in healthy women (Ayers *et al.*, 2012; Hunter & Liao, 1996; Keefer & Blanchard, 2005) and women with breast cancer (Hunter, Coventry, Hamed *et al.*, 2009; Mann *et al.*, 2012), include the modification of negative or less helpful cognitive appraisals of HF/NS as a means of managing symptoms.

### *4.4 Implications for future research*

The findings of this qualitative study describe the experiences of HF/NS in a small sample of men with prostate cancer; the themes identified are therefore valid in this sample. However, there is a need for further exploration of these themes in a larger sample of men in order for these findings to be reliably applied to the population that was studied.

It was hoped that this preliminary exploration of HF/NS in men would act as a basis for further quantitative investigation of the themes identified. This was the process used in the development of the HFBS (Rendall *et al.*, 2008). The thematic framework index produced within the study could be used, in conjunction with the existing literature about HF/NS in men with prostate cancer and information from other clinical sources, to generate cognitive-behavioural items for a measure of HF/NS in these men.

No measures of HF/NS in men currently exist and, as was found with the HFBS, such a measure could be used to identify reliable cognitive-behavioural constructs associated with HF/NS in men. A measure such as this could inform future cognitive-behavioural treatments for HF/NS in men via quantitative investigations of the relationships between HF/NS problem-ratings and cognitive-behavioural reactions. A study is currently in progress to evaluate a cognitive-behavioural intervention for men with HF/NS following prostate cancer treatment (Yousaf *et al.*, 2012); thus, research exploring such relationships has already begun and a tool designed specifically for men with prostate cancer that is able to reliably measure cognitive-behavioural change would be of great value.

# Chapter 5: CONCLUSIONS

In summary, this qualitative study has explored the experiences of HF/NS in a small sample of men with prostate cancer who experienced these symptoms as side-effects of hormone treatment. This is one of few studies specifically targeting HF/NS experiences for investigation, as HF/NS in this population are under-researched.

A number of cognitive appraisals and behavioural reactions to HF/NS were identified; cognitions about HF/NS represented a core theme, whereby there were men who reported that HF/NS had an effect on their sense of masculinity, men who experienced shame and/or embarrassment about their flushes linked to HF/NS salience and concerns about how they might be perceived by others and men who experienced feelings of powerlessness over their HF/NS. Appraisals associated with perceived control over flushes and embarrassment about flushes affected cognitive and behavioural management strategies. Some themes and interactions between themes that were identified have been reported in previous literature exploring HF/NS in men, healthy women and women with breast cancer; for example, themes related to perceived control and the way in which high HF/NS problem-ratings were associated with negative experiences of flushes. Other themes were novel, whereby appraisals relating specifically to prostate cancer and general self-perceptions, as well as appraisals associated with socio-cultural factors such as social background and ethnicity, were found to influence cognitions about HF/NS.

The proposed interactions between themes in this study supported existing theoretical cognitive-behavioural models of HF/NS and therefore these findings may have implications for psychological treatments for HF/NS in this population. However, further research is needed, based on the results of this study, to develop quantitative measures of HF/NS beliefs and behaviours and develop and evaluate psychological interventions to help men manage HF/NS following prostate cancer.

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# A P P E N D I C E S

Appendix A: The five interconnected processes of the framework method applied to this study

*1. Familiarisation*

This refers to the way in which researchers become comfortable with the source material in their research study and gain a comprehensive understanding of this material in terms of both breadth and depth. Ritchie and Spencer (1994) suggest that this stage involves 'immersion in the data' (p. 178) via reviewing both transcripts and original data sources (e.g. audio-recordings), while keeping track of any emergent themes or relevant issues using notes. The use of research notes or memos is believed to be useful at any analytical stage in order to record insights or interpretations that may be significant or relevant to the analysis (Saldaña, 2009). In this study, immersion in the data took place throughout the data collection (i.e. the conducting of interviews) and analytical process; the primary researcher transcribed all audio-recordings and during analysis transcripts were revisited alongside sections of audio-recordings. Electronic research memos were created relating to the source material and following discussions about the data with research supervisors; memos included reflections on emergent patterns, themes and concepts as well as thoughts about possible influences on these emerging ideas and the process of data collection.

*2. Thematic framework*

According to the framework method, ideas formulated during familiarisation and after reviewing memos can be used to develop a *thematic framework* that is in part guided by key research aims and questions; emergent themes relevant to the study aims can be identified and source data can be examined, sifted and organised according to these themes. Although specific research aims and questions contribute to the thematic framework that is established, this structure is also influenced by emergent

issues that may not have been considered by researchers and originate directly from the source material (e.g. discussion with participants or interview transcripts). Thus, the framework is adjusted and refined according to emergent themes when it is applied to increasing amounts of source material. In this study, a thematic framework was initially established with the study research aims and questions in mind, information from the research literature also informed the original framework. During data collection this framework began to alter and information from research memos and source material led to further alterations during both data collection and analysis.

*3. Indexing*

This involves applying the thematic framework to textual source material, such as interview transcripts. This process is systematic in that all material is considered in turn and individual units of data are analysed for their meaning and are ascribed labels or index references (thematic codes), which refer back to the thematic framework. For example, passages and sentences from an interview transcript could be annotated with index references in the margin of a page. However, there is an element of subjectivity involved in this process when making judgements about the meaning or essence of individual units of data. The referencing system helps to highlight the way in which data has been ascribed meaning and makes the process more explicit; this system can be numerical or descriptive, whereby index references are either numbers or brief textual descriptions of the data that refer back to a corresponding index of themes within the thematic framework. Multiple indexing is also possible, whereby the meaning ascribed to a unit of data may endorse more than one index reference.

The process of indexing and the re-categorisation element of charting (described below) could be described as coding and respectively bear resemblance to first- and second-cycle coding methods as described by Saldaña (2009). Thus within this study, thematic coding of each individual interview transcript was undertaken as guided by the indexing process. Coding took place electronically via Nvivo, whereby individual sentences, phrases or paragraphs were analysed for their summative meaning and code (a word or short phrase representing that meaning) was assigned; a variety of first-cycle coding methods (i.e. those that occur during initial or early coding) were

used including elemental methods (initial, descriptive and in-vivo coding), grammatical methods (magnitude and attribute coding) and affective methods (emotion, values and evaluation coding). Multiple indexing was used as some individual units of data represented differing issues however this was avoided where possible to prevent excessive indecision during coding. Second-cycle coding methods (i.e. those that require conceptualising) included pattern coding and focused coding (Saldaña, 2009). A descriptive index referencing system was used.

*4. Charting*

This follows the indexing of source materials and is a process used to establish an overarching understanding of the source material. Charting involves extracting data from sources and reorganising these data into specific themes (superordinate and subordinate themes) which may derive from the thematic framework but may also include novel themes. This process allows the creation of charts whereby comparisons can be made across all participants by theme (thematic analysis) or across all themes by participant (case analysis); this means that individual participants can be grouped according to particular characteristics and compared in terms of the themes that emerge for individuals with those characteristics. The differences and similarities within themes can also be considered because charts include carefully constructed summarised accounts of participants' indexed references for each theme, i.e. verbatim text is not simply included in the charts. All summaries are referenced to ensure that participant's original accounts are accessible and that the way in which summaries were created remains overt.

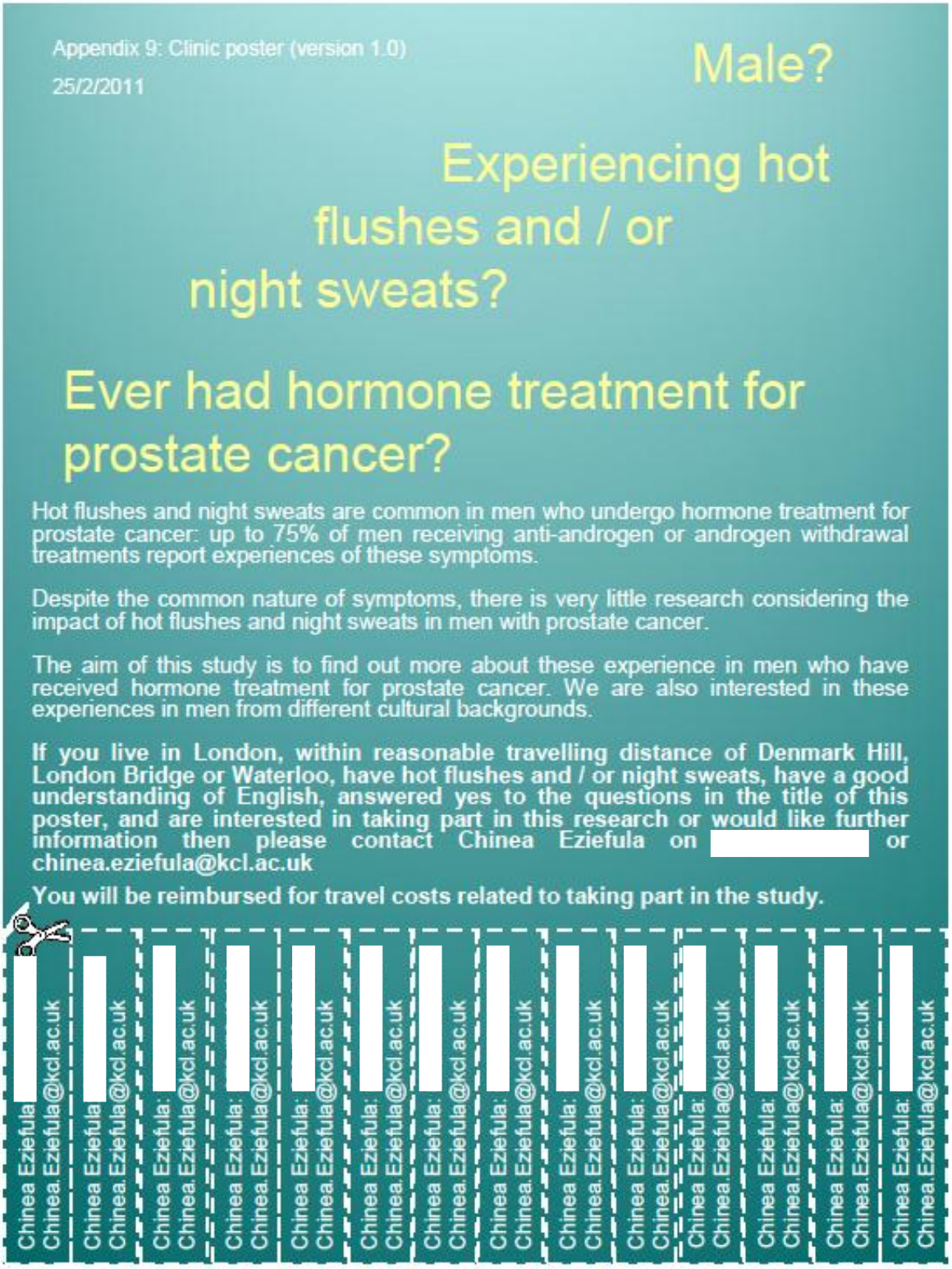
As described previously, the reorganisation of data in this study occurred via second cycle-coding, whereby codes were grouped into subordinate and superordinate themes some of which were either within the thematic framework or were introduced into it. A descriptive index of all of the themes (superordinate and subordinate themes) within the thematic framework was created; this index is illustrated in the results section, it contains all the relevant themes emerging from this study. Charts were also created containing referenced summaries of source material. These charts were structured so that thematic analysis was possible and between- and within-

theme comparisons could be made across participants with certain demographics (e.g. ethnicity) and assessments scores (e.g. HFRS and B-IPQ scores).

*5. Mapping and interpretation*

This involves consideration of all established themes (superordinate and subordinate themes), whereby charts and research memos are reviewed in order to meet the functions defined by the original research aims or questions of the study; for example this could involve using findings to define concepts, identify the range or nature of phenomena, create typologies via multidimensional thematic analysis, explore patterns and associations and/or provide explanations (Ritchie & Spencer, 1994). In this study, the aim of identifying cognitive-behavioural experiences of HF/NS in men with prostate cancer was coupled with the aim of exploring any interactions between cognitions, meanings, behaviours as well as exploring any differences in these interactions with other factors, including problem-ratings of HF/NS and prostate cancer representations. These aims are reviewed in relation to study findings in the discussion section.

Appendix B: Recruitment poster



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**Participant information sheet and consent form A (version 1.1)**

**Exploring the cognitions and behaviours associated with vasomotor symptoms (hot flushes and night sweats) in men with prostate cancer undergoing hormone treatment**

You have been invited to take part in a research study being carried out as part of a Doctorate in Clinical Psychology at the Institute of Psychiatry, King's College London.

This information sheet is designed to help you to understand the purpose of this research, why it is important and what any participant involvement would involve should you choose to take part.

Please feel free to contact us on the phone number or email address listed below, or using the postal address indicated above, if you have any further questions or concerns about this research.

**What is the purpose of the study?**

Hot flushes and night sweats commonly occur as a side effect when men and women have hormone treatments for cancer. Much of the research into hot flushes and night sweats has been conducted on women and there are now measures to keep track of the severity and impact of hot flushes and night sweats on women. Therapies have also been developed to help women to manage hot flushes and night sweats.

Hot flushes and night sweats are equally as common in men who undergo hormone treatment for prostate cancer, with up to 75% of men receiving anti-androgen or androgen withdrawal treatments reporting experiences of these symptoms. Despite the common nature of symptoms, there is very little research considering the impact of hot flushes and night sweats in men with prostate cancer.

The aim of this study is to find out more about the experience of hot flushes and night sweats in men receiving hormone treatment for prostate cancer. This will be done by asking men about what they think of their symptoms, how they feel about them and what they do to manage them. It is hoped that this information could be used to develop a list of common experiences reported by men, which could in future be used to develop measures of severity and impact of symptoms in men and could help to pave the way for the development of therapies for the treatment of symptoms in men.

Cultural differences have been found in the experience of hot flushes and night sweats in women, however this has not been explored in men. So another aim of this study will be to ask men from different cultural backgrounds about their experiences.

**Why have I been invited to participate?**
You have been asked if you would like to take part in this research because we are interested in the experiences of hot flushes and night sweats in men who have been treated with hormone therapy for prostate cancer (either in the past or at present) and who are currently experiencing hot flushes and night sweats of any severity.

**Do I have to take part?**
No. You should feel free to decide whether or not you want to take part in this study based on the information that we have provided. Your decision will not impact on any other aspect of your treatment nor will it impact on any support that you currently receive.

If you decide that you do want to take part then please be aware that you are free to withdraw from the research study at any point without the need to give reasons for this.

**What will happen to me if I do choose to take part?**
If you do agree to take part in this research study, you will be invited to attend an individual interview at a time that is most convenient to you at either Guy's Hospital, St Thomas's Hospital or the Institute of Psychiatry. You will be asked to complete and bring two questionnaires with you to this interview.

You will be given this information sheet to keep and asked to sign the attached consent form when you arrive for your interview. You will be reimbursed up to a total of £15 for any travel costs that you might incur.

Interviews will be facilitated by a researcher who will ask general questions about your personal experience of hot flushes and night sweats. This interview will last for approximately 1 hour and will be audio-recorded. All of the information that you share will be treated confidentially, audio-recordings will not contain your name or any personal details and will be destroyed as soon as they are no longer needed for this research.

**Are there any risks or disadvantages involved in taking part?**
There are no anticipated risks associated with this study. However, some men may find it difficult or distressing talking about their hot flushes and night sweats. If this were to happen, then you are reminded that you may withdraw from the study at any point without the need for explanation. The principal researcher (Ms. Chinea Eziefula) will be available to discuss the experience of taking part in the research study and can suggest further avenues of support if necessary.

**Are there any advantages or benefits involved in taking part?**
It may be helpful or useful for some men to share their experiences of hot flushes and night sweats, however it is unlikely that the study will be of any immediate clinical benefit to you.

If you choose to take part, you will be contributing to a field that is very under-researched and we hope that this will pave the way for further research into hot flushes and night sweats in men. We hope to use the information gathered from this study to add to our understanding of

hot flushes and night sweats in men and to develop measures of hot flushes and night sweat experiences in men in the future.

You will be offered the chance to be involved in future research into the development of therapeutic treatments for the management of hot flushes and night sweats in men.

**What will happen if I do not want to carry on with the research study?**
As mentioned previously, you are free to withdraw from this research study at any point during the process, including during interviews. If this happens, you will still be paid for your travel and none of the information that you may already have provided will be used, unless you give consent for use.

**What if there is a problem?**
If you experience any concerns about aspects of this research or any other issues arise at any point during your participation in this research study, you are welcome to contact the principal researcher (Ms Chinea Eziefula) or the research supervisors (Professor Myra Hunter and Dr Alex King).

If you remain dissatisfied and wish to make a formal complaint, this can be done through the NHS Complaints Procedure (please see contact details below). Compensation for harm arising from accidental injury as a result of your participation in our research will be covered by the Institute of Psychiatry, Kings College London.

**Will my taking part in this research study remain confidential?**
All information collected about you during the course of the research will remain strictly confidential. Any information you provide which is given to anyone other than the researchers will have any personal details, such as your name and address, removed so that you cannot be identified. In the unusual event that confidentiality or anonymity cannot be guaranteed, this will be discussed with you.

Procedures for handling, processing, storing and destroying your data will be compliant with the Data Protection Act 1998. This means that your data will be stored securely at all times; all questionnaires will be stored in a locked filing cabinet accessible only to researchers and interview recordings will be stored on secure password-protected computers.

**What will happen to the data collected for this study?**
Questionnaires will be scored and audio-recordings will be transcribed and interpreted with the aim of producing a final report. In this report, it may be necessary to include quotations in verbatim in order to accurately express how men have felt about their hot flushes and night sweats. If such quotations are used, then no personal details will be associated with these experiences except demographic information such as age and cultural background.

The deadline for submitting this research study is May 2012. As soon as the final submission has taken place, I will send you a brief summary of the results of the study if you indicate that you would like to receive this.

It is possible that the results of the study could be published in a professional journal at a later stage. If this is to happen, then all of your personal details will remain strictly confidential and any details that could be used to identify you will be removed.

**Who has reviewed the study?**
This study has been approved by the London Bloomsbury NHS National Research Ethics Committee (reference number: 11/LO/0497).

**Who do I contact for further information?**
Principal Investigator
Ms. Chinea Eziefula, Clinical Psychologist in Training
Address: Institute of Psychiatry, Kings College London, Department of Clinical Psychology, PO Box 78, Addiction Sciences Building, 4 Windsor Walk, Denmark Hill, LONDON SE5 8AF.
Email: Chinea.Eziefula@kcl.ac.uk
Telephone: [redacted]

Research Supervisors
Professor Myra Hunter - Professor of Clinical Health Psychology /Consultant Clinical Psychologist /Professional Lead for Clinical Health Psychology South London & Maudsley Foundation Trust
Address: Institute of Psychiatry, Unit of Psychology, 5th Floor Thomas Guy House, Guy's Campus King's College London, London Bridge, LONDON SE1 9RT

Dr. Alex King - Clinical Psychologist in Oncology
Address: Dimbleby Cancer Care Centre, St Thomas's Hospital, Westminster Bridge Road, LONDON SE1 7EH

South London and Maudsley NHS Trust Complaints Office
Maudsley Hospital, 111 Denmark Hill, London, SE5 8AZ. Telephone: 02032282444/2499

**I have decided I want to take part in the study. What do I do now?**
Please bring the consent form with you to your interview as indicated on the enclosed invitation letter.

*Thank you for taking the time to read this information sheet and if you have any queries then please do not hesitate to contact us.*

Ms Chinea Eziefula
*Clinical Psychologist in training*

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## Participant consent form A (version 1.1)

### Exploring the cognitions and behaviours associated with vasomotor symptoms (hot flushes and night sweats) in men with prostate cancer undergoing hormone treatment

Chief Investigator:
Ms. Chinea Eziefula (Clinical Psychologist in Training, Institute of Psychiatry)

Research Supervisors:
Professor Myra Hunter (Professor of Clinical Health Psychology /Consultant Clinical Psychologist /Professional Lead for Clinical Health Psychology South London & Maudsley Foundation Trust) and Dr. Alex King (Clinical Psychologist in Oncology)

*Please read the following statements and then initial the box on the right.*

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by the named researchers from the Institute of Psychiatry where this is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that interviews undertaken as part of the study will be audio-recorded and that all recordings will be treated confidentially and will be destroyed as soon as they are no longer needed for this research. ☐
5. I understand that should I take part in the interview phase, a selection of my quotations may be used in the final research report, though these will be anonymised and will not be identifiable as mine. ☐
6. I agree to take part in the above study. ☐

| Name of Participant: | Date: | Signed: |
|---|---|---|
| …….. | …….. | …….. |
| Name of Person Taking Consent: | Date: | Signed: |
| …….. | …….. | …….. |

Appendix D: Screening checklist

**Screening Interview Checklist (version 1.1)**

Participant ID: ..... Date: .....

| | |
|---|---|
| Male aged over 18 | ☐ |
| Current experience of hot flushes (at least one per week) | ☐ |
| White / Black British | ☐ |
| Any stage of prostate cancer requiring hormone treatment: Localised / locally advanced / metastatic | ☐ |
| Current / retrospective receipt of hormone treatment for prostate cancer (anti-androgen / androgen withdrawal) | ☐ |
| An ability to read, write and speak in English | ☐ |
| No Axis II DSM-IV TR diagnoses | ☐ |
| Not currently being treated for DSM-IV TR diagnoses such as mood disorders, psychosis and dementia as a primary problem | ☐ |

Any emotional problems e.g. depression, anxiety at present: Y / N

.....

Appendix E: Invitation letter

**Institute of Psychiatry**

at The Maudsley

KING'S College LONDON

University of London

Department of Psychology, PO 78
Institute of Psychiatry
Addiction Sciences Building 3rd Floor
4 Windsor Walk
Denmark Hill
London SE5 8AF

**Invitation letter (v1.0)**

**Exploring the cognitions and behaviours associated with vasomotor symptoms (hot flushes and night sweats) in men with prostate cancer undergoing hormone treatment**

Dear

You have been invited to take part in an in-depth interview with me about your hot flushes and /or night sweats. Details regarding the time, date and location of this interview as arranged during our telephone conversation are listed below.

**TIME:**……..

**DATE:**……

**LOCATION:**……

Please feel free to contact me to cancel / reschedule or if you have any queries or concerns. Otherwise, I hope to see you on the date mentioned above.

Yours sincerely,

Ms Chinea Eziefula
*Clinical Psychologist in training*

Email: Chinea.Eziefula@kcl.ac.uk
Telephone: [redacted]

A|

## Socio-demographic Questionnaire (v1.1)

Participant ID: ……  Date: ……..

Some further information about you would be helpful, so it would be useful it you could please answer the following questions. Please remember that all information will remain strictly confidential.

1. What is your:

   1.1 Age: …… (years)  Date of Birth: ……..

   1.2 Religion:……..

   ……

   1.3 Ethnicity (please tick one box):

☐ White British  ☐ Any other White background, please specify

……

☐ Asian British  ☐ Any other Asian background, please specify

……

☐ Black British  ☐ Any other Black background, please specify

……

☐ Mixed background, please specify ……

……

☐ Other Ethnic Group, please specify ……..

……

   1.4 Relationship status (please tick one box):

☐ Single / Never married  ☐ Married / Living with partner  ☐ Widowed

☐ Divorced / Separated  ☐ Have partner but don't live with them

1.5 Sexual orientation (please tick one box):

☐ Heterosexual ☐ Homosexual ☐ Bi-sexual

☐ Other, please specify .....

1.6 Employment status (please tick one box):

☐ Working full-time (30 hours or more per week)

☐ Unemployed and looking for work

☐ Unable to work due to illness or disability

☐ Working part-time (less than 30 hours per week)

☐ At home and not looking for paid employment

☐ Retired

☐ Student

☐ Self-employed

☐ On sick leave with plans to return to work

☐ Other, please specify: .....

.....

1.7 Level of education (please tick one box):

☐ No educational qualifications

☐ O level / Standard grade (secondary education until 16-years-old)

☐ Higher / A level / National grade (secondary / further education until 18-years-old)

☐ Degree / Professional qualification

☐ Other, please specify: .....

.....

2. How long have you had hot flushes / night sweats?

.....years; ..... months

3. At what stage is your prostate cancer? (Please tick one box).

☐ Localised ☐ Locally advanced ☐ Metastatic ☐ Unknown

☐ Other, please specify .....

4. What type of hormone treatment are you receiving for your prostate cancer? (Please tick one box).

☐ Androgen-withdrawal ☐ Anti-androgen ☐ Unknown

☐ Other, please specify .....

5. Have you ever used a treatment for hot flushes / night sweats? (Please tick one box).

☐ Yes ☐ No

If yes, what treatment (s)? .....

.....

.....

6. If you could choose a treatment for hot flushes / night sweats, which of the following would you prefer? (Please tick one box).

☐ Medication

☐ Attending a group to help manage hot flushes / night sweats

☐ A self-help guide to help manage hot flushes / night sweats

☐ None of the above

☐ Other, please specify: .....

.....

7. Are you suffering from any emotional problems, for example anxiety or depression, at the moment?

☐ Yes ☐ No

8. Are you receiving treatment for any mental health problems at the moment?

☐ Yes ☐ No

Appendix G: Hot flush rating scale

**Hot Flush Rating Scale (HFRS)**

## Hot Flush Rating Scale

Pp ID: ..... Date.....

How often have you had hot flushes in the past week?
Please estimate: _____ each day, or _____ each week.

How often have you had night sweats in the past week?
Please estimate: _____ each night, or _____ each week.

**Please circle a notch on each scale to indicate how your flushes/ sweats have been <u>during the past week</u>:**

To what extent do you regard your <u>flushes/sweats</u> as a problem?
no problem at all very much a problem
|____|____|____|____|____|____|____|____|____|____|

How distressed do you feel about your hot flushes?
not distressed at all very distressed indeed
|____|____|____|____|____|____|____|____|____|____|

How much do your hot flushes interfere with your daily routine?
not at all very much indeed
|____|____|____|____|____|____|____|____|____|____|

How well are you coping with them?
Not at all well very well indeed
|____|____|____|____|____|____|____|____|____|____|

How much control do you feel you have over your hot flushes?
No control at all very good control
|____|____|____|____|____|____|____|____|____|____|

How much has your sleep been disrupted by night sweats?
Not at all very much indeed
|____|____|____|____|____|____|____|____|____|____|

## Appendix H: Brief illness perception questionnaire

When completing the Brief Illness Perception Questionnaire, please answer all questions in relation to your prostate cancer, e.g. when the questionnaire refers to "your illness" please think of this as your prostate cancer.

**The Brief Illness Perception Questionnaire**

For the following questions, please circle the number that best corresponds to your views:

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **How much does your illness affect your life?** | | | | | | | | | | |
| 0<br>no affect at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10<br>severely affects my life |
| **How long do you think your illness will continue?** | | | | | | | | | | |
| 0<br>a very short time | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10<br>forever |
| **How much control do you feel you have over your illness?** | | | | | | | | | | |
| 0<br>absolutely no control | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10<br>extreme amount of control |
| **How much do you think your treatment can help your illness?** | | | | | | | | | | |
| 0<br>not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10<br>extremely helpful |
| **How much do you experience symptoms from your illness?** | | | | | | | | | | |
| 0<br>no symptoms at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10<br>many severe symptoms |
| **How concerned are you about your illness?** | | | | | | | | | | |
| 0<br>not at all concerned | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10<br>extremely concerned |
| **How well do you feel you understand your illness?** | | | | | | | | | | |
| 0<br>don't understand at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10<br>understand very clearly |
| **How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?** | | | | | | | | | | |
| 0<br>not at all affected emotionally | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10<br>extremely affected emotionally |
| **Please list in rank-order the three most important factors that you believe caused <u>your illness</u>. *The most important causes for me:-*** | | | | | | | | | | |
| **1.** _____ | | | | | | | | | | |
| **2.** _____ | | | | | | | | | | |
| **3.** _____ | | | | | | | | | | |

Appendix I: Interview schedule

**Semi-structured interview schedule (version 1.1)**

This schedule will guide each interview. It provides a loose framework for the topics to be explored by the interviewer, allowing room for participants to discuss issues that are important to them, thus the language used and order of presentation may vary.

*Introductory Stage*

- Interviewer introduces herself and thanks participant for coming.
- Aims of the interview and research are reviewed, along with an explanation about the need to audiotape interviews and make notes, the way in which this information will remain confidential and the sensitivity of the topics to be discussed.
- Interviewer provides information about the right to withdraw at any point and the right to decline to answer any questions.
- Interviewer explains the payment process and that it is unrelated to the completion of the interviewer. Payment for travel is calculated and made.
- Interviewer encourages participant to ask any questions that they may have.
- Interviewer checks that the participant understands study aims and issues and gains their consent to participate by asking the interviewee to sign the consent form. The participant signs two copies one for them to keep and one for the interviewer.
- Interviewer asks the participant not to be put off by any note-taking during the interview or allow it to stop the flow of their thoughts or responses during the interview as audio-recording will capture all information that the interviewer does not have time to write.

----------**Begin audio-recording**----------

*Interview Stage*

Tell me about your HF/NS.

***i. Sentence completion task followed by reflections and probes on responses.***

*Sentence completion items: During a hot flush, I am… /During a night sweat I am…*

Possible probes:

- What about the hot flush / night sweat causes you to feel / be…?
- Do you try to do anything to stop feeling / being…?
- How does this affect…?
- What else happens during a hot flush / night sweat?
- Tell me more about…?

*Sentence completion items: During a hot flush other people see me as…? /During a night sweat other people would see me as…?*

Possible probes:

- What makes you think this?
- How does this make you feel?

- Do you do anything to try to change this? (What?)
- How does this affect how people see you?

ii. ***Interviewer asks participant to recall a recent hot flush and night sweat, thought diary items will be used to guide the information collected (i.e. situation /context, intensity of flush, mood, actions taken, thoughts /images, interpretations – what does this say about you, your life, your future).***

Possible probes / Additional questions:

- When did your hot flushes / night sweats begin?
- What were your initial reactions? (thoughts/ feelings / behaviours)
- Tell me about a recent hot flush experience.
- Could you describe what happens during a hot flush / night sweat in your own words?
- Do you do anything when having a hot flush / night sweat? (What?)
- Do hot flushes / night sweats affect how you feel? (Emotionally, physically, mentally. How do you feel when having a hot flush / night sweat?)
- Do hot flushes / night sweats impact on your daily life? (How? What is the impact?)
- Do you think anything affects your hot flushes / night sweats? (What? How?)
- Do you think your hot flushes affect anything you do? Are there things that you avoid doing because of because of hot flushes / night sweats?
- Have hot flushes / night sweats affected how you see yourself? (How so? How much has it affected you? How did you used to see yourself? How do you see yourself now? How much of a difference have hot flushes / night sweats made to how you see yourself?)
- Have hot flushes / night sweats affected how others see you? (Friends, family, partners).
- Do you think about hot flushes / night sweats? (How much do you think about hot flushes / night sweats?)
- How do you deal with symptoms (hot flushes / night sweats) on a day-to-day basis? (What works? Does not work? - Elicit positive and negative aspects and follow up on thoughts, feelings and behaviours).
- Is there anything about your background / culture that might affect your experience of hot flushes / night sweats?

***iii. Interviewer explores cause of hot flushes and night sweats and treatment behaviours and preferences.***

Possible probes:

- What do you believe causes (your) hot flushes / night sweats?
- What do you think / feel about the cause of (your) hot flushes / night sweats?
- How are your hot flushes managed by you / others (family, friends, healthcare professionals – doctors, nurses)?
- Is there anything about your background / culture that might affect how your hot flushes / night sweats are managed?
- Are you receiving any treatment for your hot flushes and night sweats? (Have you ever received treatment? What? What did you think of treatments?)
- Do you experience side effects for treatment for hot flushes / night sweats? (What? What effect do any side effects have on you / your friends / family?)
- Do you know of (other) treatments available to deal with hot flushes and night sweats? (What are they?)
- Would you be interested in another treatment option? (Indicate preference from list if yes).

*Concluding Stage*

Interviewer explores participant's experience of interview with various questions:

- Is there anything else that we have not covered yet that you would like to say or ask?
- Do you think the interview has captured your experiences of hot flushes and night sweats?
- Are there any responses / answers that you would like to change or omit from audio-recordings?
- I hope to submit the results of this research for publication and can provide a brief report for the individuals who were involved in the research. Would you like a copy of this report?
- Would you be interested in any taking part in other research into hot flushes and night sweats? (If so, explain that they could be contacted about this in future).
- Thank you very much for taking part. Please feel welcome to contact me if you have any other concerns, questions or feedback that come to mind after you have left. My contact details (email address and phone number) are on the information sheet.

----------**End audio-recording**----------

Appendix J: Interview transcript for Pp006

**Transcript: Pp006 (rec 6)**

I: So to start off, I will just ask you to tell me about your hot flushes and night sweats, what are your experiences of your hot flushes and night sweats?

P: Um…well during the day, um I obviously feel very flushed but it's mainly my head and I sweat quite profusely across the forehead but it doesn't, I don't seem to sweat anywhere else, it's just the head but I've obviously got this sensation of being very hot just uh just in the head.

I: So it doesn't happen anywhere else for you?

P: It just seems to be the head yeah and I start sweating and it's pretty much the same with the night sweats although at night I had the sensation it was all of my body not just my head, so I have to throw the duvet off and they last for about… I would say about five minutes.

I: And is that the night sweats?

P: Yeah and I've had, roughly I think it happens about three times a night and so they last about fifteen minutes…uh sorry not fifteen minutes, five minutes yeah certainly not as long as fifteen minutes.

I: So um they last for about five minutes and then what happens?

P: It just all just suddenly disappears I mean obviously during the night what happens then if you're kind of sleepy, I then get cold 'cause obviously I've thrown the… duvet off…I don't think the body's cold, I think it's just the fact that you're laying there without a duvet cover um…

I: And-

P: I seem to have more during the day I have to say.

I: How often do you have them during the day?

P: Well probably oh God I would say between, hot day I probably may have ten.

I: And from what you've described you said you throw the duvet off at night time, yes. Do you do anything else to erm help?

P: No…I just lie there (laughs)…I kind of realised that it only lasts for five minutes so…

I: How long did it take you to realise that they last for five minutes?

P: Um… I dunno I suppose after a few, few nights when they first started, I must admit it pretty much happened, it started happening about three weeks after I started the Zoladex.

I: Okay so three weeks after the first Zoladex?

P: Yeah it started to happen and they sort of gradually got worse I would say.

I: Mmm… what was it like when they first started?

P: Um…it was like quite a weird sensation well I obviously never had anything like, I know women obviously in the menopause suffer with it quite badly but uh just a weird sensation and I say the hot flush but really mainly in the head and sort of sweating profusely.

I: What did you think was happening when they first started?

P: Well I was warned obviously that they were going to happen so I was fully aware that it was going to happen and it was explained to me that some, some men find it worse than others and I believe some men don't actually get it at all so (laughs)… but I'm not one of those…

I: So when they first started you had that sensation of the hot flush sort of um in the head, lots of sweating, what were you thinking when you first had it?

P: Um well I basically just thought well yeah I'm gonna be one of those people that will suffer from the hot flushes and night sweats…

I: And how did that make you feel?

P: Well because I sort of um…my way of looking at it was that if it's doing its job I will, I will suffer anything, if it's actually working so I can't say that I was too bothered about it…

I: Mmm… and I know you said that they gradually got worse after the three weeks, um when they got worse, what were you thinking when they got worse?

P: Um well again I sort of… expected it because basically the consultant I first saw said that you know if can be quite severe so I was quite prepared for it…

I: So being prepared, you said your consultant told you about it, do you think that has made a difference for you?

P: I think definitely, oh yeah I think I would have been quite worried if it hadn't been explained to me.

I: Mmm…

P: I have to say the information that I got about what was going to happen was very good.

I: Mm hm and who did you get the information from?

P: Um the consultant I saw was a Miss XXXX um that would have been at um the erm XXXX (hospital)…

I: Mmm and so um you were kind of aware of what was going to happen when you had them and then what do you… what have you been doing to try to deal with them I suppose?

P: Well I thought a bit of homeopathic medicine… and I had various people, I have to say mostly women, who said try taking you know menopausal tablets and that but I did start taking…um s-sage tablets which I was told were very good but can't honestly say that I've found much difference…uh I kind of wanted to ask somebody, does that actually interfere with, with what the Zoladex injection are doing if you see what I mean, I'm not really sure so I probably need to speak to somebody you know if there is a … so I spoke to XXXX last week and she said that there are tablets and patches that can be used but I actually asked her obviously does that interfere with the Zoladex but she didn't really know so I'd have to ask.

I: How does that affect you when you're thinking of ways to manage the hot flushes? So thinking about whether or not it interferes, how does that affect the plans that you might make?

P: Well I can't, that is it, exactly I'm just worried that anything I might take may affect the err the effectiveness of the injections.

I: Okay… So does that affect whether or not you do take things?

P: Um well I'm kind of thinking  if it's homeopathic it's…you know it's a herbal remedy I would imagine that it wouldn't have any effect but… I don't, I don't actually know that.

I: Mmm…and then so do you think anything affects your hot flushes or night sweats?

P: Um, very often if I have a cup of tea or coffee um… … yeah sometimes they bring it on…basically any hot drink.

I: Does anything else affect them?

P: Uh I can't actually think of anything that directly causes it no…

I: And with those things do you, does being aware that they affect them, does it change any of your behaviours?

P: No it doesn't really no no.

I: And why's that?

P: Um well I just think that I've come to expect it and I'm, like anything, I'm getting used to it.

I: Mmm…so you said you feel like you're getting used to it, can you tell me a little bit more about that?

P: Uh well 'cause I know that it's the side effects of the Zoladex um I'm kind realising that that's something I'm going to have to put up with… but I kind of think, I'm quite prepared to do that if the Zoladex injections are doing their job.

I: …And so we spoke a little bit about your initial reactions to the flushes and I wonder if you can think about a recent flush that you've had and if you could kind of describe it to me.

P: Yeah um that would have been in the early hours of this morning, uh about four o'clock and it's always the same pattern you know I wake up really hot and sweaty but basically my head, well you feel quite hot all over but it's only the head the sweats you know so like the forehead and just the top of my head and then as I say basically lasts for about five minutes… and when it's finished I just go back to sleep.

I: Okay so this was early and a night sweat?

P: Yes yeah not really had one much this morning.

I: And then did you do anything when you were having it?

P: No I just lay there and wait for them to go (laughs).

I: When you're waiting for them to go, what goes through your mind?

P: Um… I mean I've got to be honest um I feel and again I know it's one of the side effects of the injections is that I feel slightly depressed and you tend to think about the cancer…

I: Okay… mmm…

P: …but again I know that's one of the side effects so I've…gradually sort of learned to deal with it.

I: So one of the side effects of the Zoladex is to feel sort of depressed and feel it changes your mood?

P: Yeah, yeah…yes I mean when I was having radiotherapy talking to all the others guys who've got prostate cancer there some of them seem to suffer with it really badly but I can't say that mine is, it's really bad…in fact some people there were on medication because they felt so depressed but I'm certainly nowhere near that.

I: Mmm… and I know you said that you tend to think about the cancer if you're sort of lying in bed, what sort of thoughts do you have?

P: Well quite depressing thoughts really…

I: Yeah…can you, if you're comfortable with telling me a little bit about them…

P: Um well my wife died of cancer just… well over seven years ago now and you know basically watched her die I mean…not very nice so…

I: And so do you think about, what would you think about her or what would happen?

P: Yeah I think about her a lot yeah…

I: Okay…when you're um sort of lying in bed and you've got those, does that, do thoughts come up because of the hot flushes or do they come up anyway?

P: Um they probably would come up anyway I think yeah… I mean sometimes I actually sleep right the way through it, I go back, if I'm having it I might wake up just for a few seconds…

I: The flushes?

P: Yeah… and then I just go back to sleep and then I wake up again 'cause I'm cold 'cause of the duvets.

I: Mmm… and with the depressing thoughts so you think about your wife and do you ever think about what might happen to you with the cancer?

P: Oh yeah absolutely, I think that would be fairly common I would think, you know with anybody with any form or cancer or any other illness.

I: Yeah.

P: Yeah, yeah.

I: And what type of thoughts do you have?

P: Well grandchildren, I've got three grandchildren…um you think about not getting to see them grow up and that type of thing… but I'm not overly worried about it 'cause I kind of know that it's one of the side effects… of the treatment and also… you know they're probably quite natural thoughts.

I: …and so you said you sometimes sleep through the um night sweats…

P: Yeah sometimes I do yeah.

I: Yeah and you said you wake up for a few seconds and then you kind of-

P: Well I wake up 'cause I put the duvet back on 'cause it gets a bit cold yeah.

I: And then so, do you think your hot flushes and or night sweats affect how you feel and not just physically but maybe emotionally as well?

P: Um…no, no, not really, you kind of look at all of this is that if it's doing its job I'm quite prepared to put up with you know uh any side effects…

(Pause)

P: And sometimes during the day I mean it can be embarrassing during the day 'cause I mean people look at you and wonder why on earth you're sweating like that and you might even have a bead of sweat off the end of your nose (laughs).

I: Mmm…and what makes it embarrassing during the day?

P: Well yeah if people look at you and think that you maybe it looks like I don't know maybe it looks like you're ill or…

I: Okay.

P: I tend to just get my handkerchief out and just mop my brow.

I: Mmm…and so when you're having the flush, do you think that having the flush in public is different to having it when you're on your own?

P: Um well people that I, friends I know know that it's one of the side effects so they, they just sort of tend to laugh (laughs) uh so you know you could be somewhere in a shop and I can imagine that it looks quite uncomfortable… but I'm not that self-conscious anyway so it does-that doesn't really bother me.

I: Okay… and then um…if you did, so you gave me an example I think if people did see you having a flush, what do you think might go through their minds if they saw you having a flush?

P: Well thinking that I was either panicking or… erm…yeah… I don't actually know whether it's really happened but it's just the perception you think that if…

(Pause)

P: Who knows when the winter comes I might actually be looking forward to them (laughs)…

I: And then do you think your flushes impact on your life, your daily life?

P: No I don't…

I: Is there anything that you don't do um as a result of the flushes?

P: No.

I: Or is there anything that you do as a result of the flushes that is different to what you would usually do?

P: No.

I: Do you ever avoid certain places or avoid anything?

P: No. I just try to live life as normally as possible.

I: And do you think there is anything that affects your flushes um apart from the hot drinks you mentioned?

P: No, no I certainly can't think of anything.

I: Do you think that there is any sort of state of mind that you're in that could make them worse or make them better?

P: Not…not that I'm aware of.

I: And do you think that erm, they ever happen more in certain situation compared to other situations?

P: I can't honestly say that that's the case either.

I: Mmm so when they happen do you think they're erm, yeah when do you think they happen, I suppose the question is more about if they don't happen more often do you think they just happen randomly?

P: Yeah I think they're happen randomly that's my perception of it…

I: And the night sweats compared to the hot flushes is there a difference between the two?

P: Err I just have the sens-maybe it's because you're lying down I just have the sensation that it's the whole of my body that is hot and not just my head but during the day it just seems to be my head… but I've noticed that that might be the fact that I'm actually lying down…

I: And do you think your hot flushes and night sweats have affected the way that you see yourself?

P: No…no not at all.

I: Um… have they made any difference to the way that you see yourself at all?

P: No not really no.

I: Has it, have they affected how other people see you so it could be friends, it could be family, it could be…

P: No I mean obviously friends and family, they can see when I'm sweating they just know obviously the knowledge (laughs) that I'm….having a flush.

I: And I know that you, and you mentioned that you got advice about how to deal with the flushes from people that you know.

P: Well only, it was mainly for uh women who said that they take a menopausal tablet or something oh you should try those, but I kind of would like to speak to somebody and maybe they could advise me whether there was anything… XXXX actually did say that um…um…evening primrose oil and stuff like that could help …but as I say the only thing that I did try was the um sage … somebody else then said to me that you have to take them for probably a month or two months before they would have any effect so … I probably haven't taken anything long enough for them to work anyway so…

I: So for you sage how has it affected the flushes?

P: I don't know if it did at all (laughs) but if that's true that you've got to take them for over a month for them to have any effect then I didn't take them for that long…

I: And when you got the advice so who were the women you got the advice from?

P: XXXX and women at the golf club, I play golf, kind of like just yeah…

I: And when you're asking for advice, how did it come up?

P: Uh…I think some people actually knew that men with prostate cancer who are on hormone therapy do actually suffer from hot flushes…

I: … So um how did it come up the sage as an idea for dealing with the flushes?

P: Again I think it might have been one of the women said I've heard…I think XXXX said something about or something else, I can't think what it was not but it was another herbal thing that she said other men had said had worked.

I: How did it feel getting advice from the women at the golf club?

P: Uh strange (laughs).

I: Yeah? Can you tell me a bit more about that?

P: Well…it's…you know I mean probably not many people would know that one of the side effects of treatment is flushes because it's usually the sole domain of women in the menopausal years isn't it, but they I mean, you know I'd imagine as you said on the phone, there's quite a lot known about women's hot flushes and they put 'em on HRT and sorts of things don't they…

I: Mmm.

P: But… I've not been advised to go on HRT by the way (laughs).

I: (laughs) …so um yeah so you said it felt strange talking about it with the women, so what was strange about it?

P: Well yeah I suppose…well…it was quite funny really.

I: And it, did it being funny have something to do with the fact that like you were saying the flushes being linked to the menopause and is that why it was quite funny to be talking about it?

P: Yeah 'cause I would imagine that a few women would not have real-would not have known that…

I: …okay so they were just quite surprised?

P: Yeah, yeah some of them yeah, yeah.

I: Yeah…and so…were you informing them a bit about your hot flushes?

P: Yeah, probably was yeah, yeah…definitely…

(Pause)

I: And how does that feel just I suppose having flushes and knowing that not many people know it happens in men, how does that feel?

P: Err I suppose, uh it's a bit strange I mean it-it doesn't bother me, it doesn't bother me but uh… if anybody asks I do say well you know this is what happens…

I: … do you think that um people who don't know about it in men, do you think that affects how they might see you if you were having a flush?

P: Uh no I don't actually think it seems to make any difference to be honest…

I: Mmm…and so I've asked you a little bit about some of the symptoms and you said at night you sort of pull the bed sheets off-

P: Yeah, try and cool down yeah.

I: Yeah and on a daily basis do you do anything to try and manage them, like to try and deal with them I suppose?

P: No I don't actually but XXXX said that she is going to refer me to… uh… XXXX and she… to be honest I'm not actually, something to do with uh cognitive… do you know that?

I: For some cognitive…?

P: I mean in other words she said it's like therapy to try and mentally deal with… to deal with them…

I: Mmm.

P: I've not actually heard anything but it's probably, probably early days yet…

I: Mmm what do you think of that?

P: Yeah I'll give anything a go yeah definitely.

I: And what do you think mentally dealing with them means?

P: Well she kind of explained to me that um… you know to get into a routine, to think about something cold and the experience of being cold… um… and that's really all I know… and also she suggested that I get at the uh …I get six... sessions with a massage that apparently is supposed to be very good…

I: Ah… and how would that-

P: Absolutely I said to XXXX and she said I don't know but apparently it's, it's quite therapeutic for flushes… so I will enquire about that you know yeah, yeah.

I: So it sounds like you have a plan for things to do about them in the future um in the near future.

P: Yeah, yeah.

I: Is there anything you do now like I know you said you kind of wipe your brow sometimes and just get rid of the sweat…

P: Mmm.

I: Do you anything, even little things like that, do you do to try and deal with them in the moment?

P: No not really, certainly not mentally…I…I just think you know it's uncomfortable but I know it won't last very long…

I: Okay… … and do you do anything to help with the discomfort ever?

P: No not really, I don't…

I: …and so if you're sort of hot and you're on public transport or something…do you ever... do anything… just to cool down?

P: Uh yeah sometimes I've taken, if I've got a jumper or something like that I've taken a jumper or jacket off…

I: And then what do you do after that then?

P: Well usual- sometimes, I mean obviously again it's like at night again sometimes you feel cold again and…

(Pause)

I: Okay… and so is there anything about your background um or anything that's happened to you or you're culture or anything like that that has affected the way that you deal with the flushes like mentally and you know otherwise…

P: No not really other than thinking… again from a men's point of view, not realising how uncomfortable it is for women (laughs) which is uh… something that most men would never experience.

I: Mmm… so you said not realising how uncomfortable it was err it is for women and-

P: No most men wouldn't have a clue I wouldn't have thought.

I: And now you do kind of know… what does it make you feel? How is that?

P: I do yeah (laughs) appreciate it… yeah only just that it's quite a strange thing to realise because I you know obviously post… you know I've obviously heard it for the flushes that women have but… I don't think they fully appreciate whatever they go through I mean to the extent as I said early that they are sometimes on HRT and all sorts of things…

I: Mmm… and now you've been through it, has that changed your um views about women's menopausal-

P: Yeah absolutely yeah, yeah.

I: And how has it changed?

P: Well I've seen a lot really how dramatic it… it could be…

I: Okay…

P: (coughs)

I: …and I noticed you used the word dramatic, is it-

P: Well dramatic is a… a bit too strong a word… how uncomfortable, say uncomfortable…

I: …Okay um so I'm going to ask you to just complete some sentences for me, so just I'm going to read them out and I'd like you to just complete them in your… err I'll write them down so if you could just say them out loud…

P: Okay.

I: So… during a hot flush, I am…

P: Um… well the first thing is I'm sweating…

I: Mm hm…

P: You want anything else?

I: Uh yeah anything else?

P: Erm… uh uncomfortable…

I: Mmm… anything else?

P: No not really CE no.

I: And err what about so… do you do anything to try and stop the uncomfortable feeling?

P: No other than the fact that and it's probably like that with anybody, most people is that erm… because I know what to expect… you know I-I deal with it.

I: Mmm… and when you say you deal with it, what does that mean?

P: Uhh well it means I know how it I pretty much know how long they're gonna last and I know it's not something that carries on… uh for a long time…

I: Yeah… um and then… during a hot flush, other people see me as…

P: Again, (laughs) sweaty…

I: Mm hm, yeah…

P: No I can't think of anything else just they see I'm sweating…

I: Okay.

P: I mean the colour of my face doesn't change which is really strange you'd think that you would… actually flush and you sort of glow a bit but I don't (laughs) I just sweat.

I: Yeah, yeah… so it's just that sweaty feeling and other people would just-

P: Yeah… I mean basically it's just across my forehead you know, even though-I almost look a bit like now… you know it's uh I feel slightly flushed now but it's not as bad as it can get…

I: Mmm… okay… and yeah so other people see you as sweaty, do they see you as anything else during a hot flush?

P: Uhh nobody's said anything…

I: Okay… do you think they… what do you *think* they might see you as if they see you as sweaty, is there anything else that comes up?

P: Well only I said before really… the perception that I might not be well… nobody's actually said that but it's just my… my feeling.

I: Yeah… okay and what about during a night sweat, so during a night sweat I am…

P: Um well sweating and… but uh… my body feels hot, not just my head… but I don't know whether that is just the fact that I'm… lying down whereas during the day you're standing up, I don't know maybe that's got some bearing on it… (coughs).

I: Anything else about during a night sweat… I am…

P: Um well I suppose obviously the biggest thing about the night sweats is disturbed sleep…

I: Yeah… and can you tell me more about that?

P: Well other than the fact that before I was taking it I would sleep pretty much completely through the night whereas now probably on average I probably wake up three times… three times a night… you know maybe more and sometimes less so there's no sort of set pattern with it…

I: Mmm… and how do you feel about that… that you know before you didn't wake up and now you wake up?

P: Well it's something that I'm going to put up with… uh if-if it's doing… you know if it's dealing with the cancer…

I: Mmm… and I know you said so you know you're going to have to put up with it… so it sounds like it's something that is not pleasant but you'll put up with it and so what is unpleasant about it or what types of things would you be putting up with?

P: I would probably say that that is the one thing that I notice more than anything that my sleep is disturbed.

I: Yeah, yeah…

P: Um…

I: Does that ever affect you during the day?

P: It doesn't seem to no… I mean I was told that another side effect of the hormone treatment is a general feeling of fatigue um…

I: Mmm… are you experiencing that?

P: Um…yeah I do get quite tired at times but … uh it-it's nothing I could say is bad, it's not affecting my life at all…

I: Mmm… … and so during a night sweat other people would see me as… if they could see you, other people would see me as…

P: Um… uh quite hard to described that (laughs) um… sort of err… well obviously sweating and uncomfortable and obviously throwing, throwing the duvet and covers off the bed…

I: …Okay so anything else for that one…?

P: No, I can't think of anything CE, nothing springs to mind no…

I: Great… soo um I asked you a little bit just before um we started recording about what you thought caused the hot flushes and the night sweats so err can you tell me a little bit about what you think causes them?

P: Well obviously the hormone, hormone therapy…

I: …and what do you feel about that cause, the hormone therapy causing it?

P: Well I just feel that it's a side effect that I am fully prepared to endure… um as part of the treatment…

I: Um… do you have um… any other side effects of the Zoladex?

P: No… no… well I suppose the only other thing is feeling slightly down and it's really only in the mornings and it doesn't last very long but again I was told that that could well be a side effect and I understand some people get it quite severely but I… I haven't.

I: When you have had that feeling, feeling down in the morning does it um does that affect the things that you do?

P: No I don't allow it to.

I: Yeah… does it ever change the way you react to the flushes in the morning?

P: Um no I can't say that it does CE, no… …

I: … Are there any other um situations or feelings that might affect the way you react to your flushes, so sort of that feeling of that you know it's gonna last five minutes, does that um thought sometimes not come up?

P: No I mean in some ways during the day I've almost learned to ignore it.

I: Mm… aand um how are your hot flushes managed by other people around you so that could include family, friends-

P: No no they just all accept it.

I: Do they ever do anything to try to help you?

P: No except the women (laughs) constantly give you advice (laughs).

I: Okay (laughs) so the women are giving you lots of advice… … and um… have you found, 'cause I know that you said the sage wasn't so useful but have you found other advice that they've given you helpful?

P: Oh just…far too many to mention (laughs)… suddenly brand names and things…that I could hardly just… I couldn't remember any of them… except XXXX said that evening primrose oil you know… she did say she did mention something else there but I… I can't remember that either…

I: How do you find being given all of that advice?

P: Yeah I mean it's all well intentioned so… um… yeah I feel that it's quite, quite good that uh… you know that I'm getting what people want to see better.

I: Does it always feel like that?

P: Yeah a bit really but I mean I've got have to be honest sometimes it's a little bit tongue in cheek 'cause uh…

I: …so sometimes what happens? It's a little bit tongue in cheek you said?

P: Well yeah I mean well women so… you know… actually taking the mickey really.

I: Okay… and how does that feel?

P: That (laughs) doesn't bother me at all…

I: Okay… are there ever times when that doesn't feel very nice?

P: Nah, no it really doesn't, doesn't bother me at all.

I: And so do you know of any other treatments that are around to help with your hot flushes and night sweats?

P: No I don't actually…

I: …and then would you be interested in any other treatment options that are out there?

P: Yeah I probably would yeah…

I: You did say actually that you would yeah…

P: Yeah I'm just really not sure but I've not actually spoken to anybody where I can actually ask the question is a herbal going to actually affect… the um… the hormone therapy.

I: Mmm… so it sounds like you would be interested but you want to just be sure that it doesn't affect what the hormones are doing?

P: Exactly.

I: Yeah… I know there's a question in this questionnaire about treatment preference, I think that you ticked medication would be err…

P: Yeah… only 'cause XXXX actually said that there's a patch and medication but… I'm not sure what she actually said but she thought that somebody had said that it seems like the medication may be better than the patch but again I really need to speak to somebody about that.

I: Mmm…

P: Come to think of it, XXXX sent me some literature and there was… I think where it did mention evening primrose oil and there was something else in there so I'm kind of thinking that if it's in an official letter like that from Guys and St Thomas' then it must be okay not to affect the hormone therapy but… I'm not sure…

I: Mmm… okay… erm so I know you said you started the sage and you stopped after, how long did you stop after?

P: Erm I stopped, I think it was like a jar with a month's supply…

I: Okay so when it finished?

P: Yeah I didn't bother…

I: And when it finished what did you think about how effective it was after you finished the tub?

P: Well by then I'd had so much advice on all the other things, I thought I might be wasting I think it was about fifteen pounds a jar and I thought that I was probably wasting money here…

I: Right, ah okay…

P: …It's kind of like if I don't know maybe a doctor or a therapist or something said well look this is the best stuff to take and it will have no effect I would stick with it but… at the moment I really am enthralled as to uuh you know anything to help.

I: Yeah… so yeah that's the other question so how do you think your flushes have been managed by professionals around you?

P: Uh well really the only, I mean at the beginning I was told that it will happen, uh very rare for it not to happen for most of the men on the hormone therapy… um and really the only advice and things has come from XXXX and the literature she sent me…

I: And what do you think of the input that you've had from, from those people?

P: Yeah you know I just feel that I would like to talk to… somebody… and I'd like to know whether there's a sort of homeopathic or otherwise… uh you know to counteract the flushes…

I: Mmm…

P: But I say overriding all of this you know I'm not letting it affect my life… you know it'd be great if they didn't happen but I'm not bothered 'cause for me the overall underlying thing is it's working, I mean if it's working that's fine…

I: Okay… great okay so, is there anything else that we haven't covered yet that you would like to say or you'd like to ask because that's sort of most of the questions I wanted to ask, is there anything that we haven't covered that you'd like to?

P: No not really CE no… I mean no not really.

I: Okay and do you think that the questions I've asked you in the interview has captured your experiences of your hot flushes and night sweats?

P: Yeah I would say so yes yeah.

I: Are there any answers that you'd like to change or that you wouldn't like me to keep in there?

P: No, no not at all.

I: Okay so the idea is that I would submit the results of the research that I am doing for publication uh depending on how it goes uh if you'd like a report of sort of what

um the people who are involved normally we produce a little report that just says kind of what we found and what people said about the flushes if you're interested in that then I could send that to you.

P: Yeah… yeah I'd be very interested actually yeah… yeah there's kind of there's no point in being involved in it if you don't really know that there's an outcome so no I'd be very interested um…

I: And then, would you also be interested in taking part in any other research that involves hot flushes and night sweats?

P: Yeah, no I'm up, up for anything.

I: Yeah okay so if you are, is it okay for me to pass your details on to be contacted so they'd just like tell you about it and you can choose whether or not you want to do-

P: Yeah, no that's fine.

I: Okay and apart from that I just want to thank you so much for taking the time to come.

P: No it's alright CE no I just hope that there's a you know a positive result from it all.

Appendix K: Interview transcript for Pp019

**Transcript: Pp019 (rec 9)**

I: I'd like to start by asking you a little bit about, I'd like you to tell me about your hot flushes and night sweats, just tell me about them.

P: Well initially they started err… not immediately that I had the treatment, it was probably… about three or four weeks after and I didn't realise that they were hot flushes, I just felt that there's something wrong with me in actual fact you know because… they were coming…pretty fast you know err initially you know I was getting them every day!

I: Gosh.

P: And err I started to get worried about it so um my wife had an appointment with the GP and I said see if you'll just let me ask you one question right 'cause she had my notes… and um he said yes um it's quite common you know the hot flushes with the treatment you're having… and so I just left it at that and gradually they-they turned off you know as to… erm… whereas I was getting them more or less every day, they turned off to… a variation of sort of Sunday you'd get it, Wednesday you would get it and then perhaps Friday you would get it and then you wouldn't get it for a couple of days and now it's say after this say ten month period really it seems to have, with me personally, it seems to have I thought it's a pattern since I spoke to you last week, you know… erm whereby I've been getting it sort of every other day…

I: Mmm…

P: But what I did notice is peculiar, I hadn't noticed it before, the weather was hot last week, very hot and err I was going to have an ice cream and I went into Marks and Spencer's… I had had no hot flushes at all… as I went into Marks and Spencer's into the food department and it was ice cold… I had just walked into that and the flush came straight on me as I hit the ice cold air… and that's happened two or three times since then so whether… weather affects it as well I don't know or whether that's just a sheer coincidence you know …

I: Mmm… and how many times did you say that's happened, where you've-

P: That's twice that's happened now both in the same shop you know… erm but I've not been looking for that in actual fact I mean it comes on you, it comes on you… sometimes it's worse than others though you know it's a really… you get a minor flush and then you get a really heavy flush as I would call it you know and you're …

perspiring… you know… and I don't normally perspire like that and you think it's oh crikey and you're like this (gasps and motions a wiping action)… you know, blimey…

I: Like wiping yourself off like that.

P: You know, it does really… it doesn't overcome you as such it just um… how can I put it… it just grabs you sort of thing you know… it shocks you for a second or two you know 'cause it sort of seems to come up through your body… you know… CE you know… and uh it's a very peculiar sensation I can understand how women have it for years like my wife's been saying and uh… but I never would have thought men… have this… not at all… you know, but now… it's not something that you can control you know… it'd be nice if you thought to yourself, right I'm gonna get twenty flushes this week lets have four on a Monday, four on a Tuesday and so on… there's no way of telling when it's coming or what is bringing it on you know… the only thing I can think of is… the Zoladex… is bringing it on… you know… because before I started the treatment, I never had it… so it's either the Zoladex or the radiotherapy…

I: Mmm… yeah, yeah…

P: Although if it was the radiotherapy, that didn't start… I think 'til after the first month or two… and the flushes started before that, the treatment… so it… I would imagine that it's the hormones that are causing the problem you know… I mean I understand, when I met one of the doctors and they said to me like you've got to start this treatment you know…um and there are a couple of problems that men face, anxiety problems which are around the waist if you get a belly you know and your breasts… which they do you know… there! But uh XXXX [a friend with the same problem] and I just looked at it as if crikey if that is all you've got to put up with… a bit of larger breasts… and the tummy… and you're gonna live then so what! You know… just put up with it…

I: Yeah…

P: But flushes… are the most peculiar thing I have ever known…

I: So when you-

P: When I first got the first one… it frightened me in actual fact, it really did frighten me 'cause I was out on me own in the street and it came over me… and I don't kid ya, it really did frighten me… I wondered what was happening to me… you know…

I: What did you think was happening?

P: I didn't know! I just, it just sort of… I thought to meself there's something going wrong with the treatment immediately you know and uh, I don't… well in actual fact it was um on metal railings by the park and I just rested against those 'cause I was…

and I think because I was worried, it was coming on more! You know… so whether that is another sign of it… you know worry makes it… last a bit longer… but that first time… crikey that must have gone on for… twenty minutes… must have been twenty minutes… and I was really I wasn't frightened… I was worried you know… and it was the most peculiar sensation that I've ever had in my life, that first one… but since then and the GP saying like, this is a common factor like for some men… you know um I can't really give you anything… you know… uh and I've just now accepted it and I can't control it (coughs)… excuse me… I can't control it, it just comes when it feels like it's gonna come… as I say I got up this morning, sat down for breakfast… whoof! On it came… you know… I hadn't started eating breakfast, had a cup of tea, anything at all… all I had was perhaps half a glass of water you know and it came on… and then uh oh tell a lie! I went to the GP…

I: On Monday?

P: Yeah to have that injection as I said for the uh flu…

I: Yeah.

P: and uh… it came on… like oh I can feel that coming on and it went (clicks fingers) like that, you know I legged it and went into the station which is only five minutes away and got on the train… whoof! You know and… so there's no telling when it can happen.

I: Mmm… it sounds like very unpredictable.

P: Oh yeah it is yeah absolutely… you know… and uh you can't say like XXXX says he gets them as well, you can't say, you're talking to him on the phone and then he goes phwoar I've got a terrible hot flush, you can't say to him oh I've got that the same time, it doesn't work… like that it just comes when whatever it is feels like it wants to come.

I: And do you do anything when you have a flush, like to try and manage it?

P: Well if I'm indoors I just sit down, you know… uh I'm just wondering whether it I mean when I went into Marks did I do anything? …No… I just stopped when it came on when I was in Marks you know 'cause I had the trolley and I just stopped for a minute and uh… and then carried on… with the flush being on but carried on shopping you know…

I: Yeah.

P: Because you can't let it… take over your life as such, I mean if you were out walking down the high street you can't just stop and sit on the kerb sort of thing you know but it does hit you sometimes when you're walking along and you think gosh it's come on, like that, you stop shut your eyes for a minute (takes a deep

breath) and you know you're like that, taking a deep breath, and I think you try all different things, take a deep breath, sigh, yawn… none of them get rid of it though, none at all!

I: I suppose if you're doing that like taking a deep breath what are you hoping to achieve?

P: Well you're just hoping that by taking a breath you just think (takes a deep breath) and relaxing that it will go but it doesn't, it goes when it wants to go…

I: Yeah, yeah…

P: I call it "it" because that's what I've named it now…

I: You called it "it"…

P: Mmm.

I: Okay… and I know you said you can't like if you're out you can't let it take over your life…

P: No… no. No.

I: Like you can't stop and sit on the kerb, why is that, that you can't?

P: I think I'd be too embarrassed to do it you know… um… although in saying that the first time as I said to you when I got the first one you know I stopped to go into the park and everybody was going to work and I just rested against the railings you know but uh I don't think anybody took any notice of me at the time…

I: Yeah.

P: But that was the most worrying period and I haven't had anything like that…

I: Like that?

P: No... since that first one.

I: Just to go back a little bit and think about like you don't think anyone noticed on that occasion, do you ever wonder if people notice?

P: I think they do… you know because we've been out for a meal or something like that… you know you're sitting at the table with people and then all of a sudden it comes on and you're going like this (breaths out) oh crikey… innit hot! You know… and you're trying to distinguish whether the restaurant you're in is hot or whether it's the flush… you know…

I: Mmm.

P: I mean my wife likes the heating indoors high you know ‘cause she’s a very chilly mortal…

I: Okay.

P: But even with that on, if I’m red hot indoors, I can distinguish the flush between that heat indoors… you know and mean she does have it high my wife…

I: So for you what’s the temperature like comparing the flush and the room temperature if the place is warm?

P: It’s not so much the temperature… it’s the feeling… it’s the feeling of the flush… like it sort of progressing through you like you know… and it sort of goes… it sort of goes upwards with me… it doesn’t sort of go flush on me face sort of thing, it seems to like… as if it’s someone getting a hot fan and putting it right up to you, you know and then it goes up over your body like that… I think it’s one of the most peculiar things I’ve ever tried to explain to anybody you know… I mean I’ve spoken to different guys like you know in passing like… and I say crikey innit hot and they go no it’s not… and then I go no it’s another flush like that and they go oo d’you get those then XXXX (name)? I say well I never used to only since I’ve had this treatment and I do believe that it is that… what causes it… I mean... I told you the other chap who was there XXXX, what’s his surname… XXXX, you know um…he gets ‘em… you know… and he gets what I get, an itchy tummy! You know…

I: You get an itchy tummy?

P: Yeah, you know… so you can go like this with it (scratches stomach) you know… so whether that’s to do with the radiotherapy or not…it’s you know… and that’s a peculiar thing… you don’t get it, all of a sudden you get it you know you have a good scratch it goes away and then… you might go a week or so and all of a sudden it… you’re like that, scratch! (laughs).

I: Yeah, yeah…do you have any other side effects then, other than the flushes?

P: No, no, no…no I haven’t had any other things you know erm… XXXX [Pp018, friend] has he had diarrhoea and sickness and that and uh… some of the other guys did um… tiredness is one of the most err… side effects I suppose… but I mean I said that to my wife and she said, hang on, she said, it’s two-fold this, you’ve had the treatment, she said but let’s start remembering XXXX (name), you’re sixty-six now … you know…

I: Mmm.

P: I mean before I’d have run from the station here, you know… wouldn’t be a problem but I couldn’t do it now you know…

I: Yeah… so you're wife's saying that maybe it's not that maybe it's age or-

P: As well… both or a bit…

I: -or a combination?

P: Yeah a combination of the two perhaps… now XXXX [Pp018, friend] he's err… he's about five years younger than me I think you know… and he gets terribly short-breathed… much more than I would you know so… it's hard to put into perspective how to err… how it works really.

I: Mmm… so do you think you're flushes impact on your daily life then?

P: Not now… initially, yes it did you know because of the worry of it.

I: And how did it impact on you initially in that way?

P: You're frightened… that was the thing, that's how it impacted on your life… I sat worrying about it all the time you know… 'cause you sit indoors thinking… sitting on an armchair saying to meself when is it going to come on again you know… err… but it didn't work like that CE you know thinking about it now, you're thinking right I'll sit here and it'll come on then it'll go... but it didn't…

I: Yeah.

P: I mean I could be sitting talking to you now fine right which I haven't got it at the moment and also it just goes click, it's like someone turning a switch you know and it just comes on… it's the most peculiar thing ever… I do sympathise with women (laughs) I really do!

I: Yeah… I know you mentioned that like women's flushes and women have had these, how does it compare with your flushes?

P: My wife would say um… that hers were much more regular for her than it was for me… I mean she had years ago had… um hysterectomy right so they had to do um… hormone implants and stuff like that for her… and tablets and all that… I mean she's off of them now of course… but uh she used to, terrible with 'em she was you know… and of course as a man I used to be like oh for God sake give it a rest you know…

I: Mmm.

P: But looking back now I mean I'm like hell I wish I could apologise because I do understand… you know… what uh women must go through with this you know… very uncomfortable.

I: How does it feel having something that is commonly seen to happen in women and not very common in men, how does that feel?

P: Uh… unusual really because I didn't think… I thought our two bodies were totally different, male and female… just ask yourself there you go (laughs) but um… uh I thought that sort of like internally we were totally different you know, I mean I know we've got limbs and kidneys and all that but um when it comes to hormone problems and stuff like that… testerone… I mean we all know testerone gives you that get up and go feeling doesn't it you know and with the… Zoladex hormone treatment, that… sort of staves it back, sort of thing… the err cancer you know… so I would imagine that… I don't know whether… women… get hot flushes if they don't take-that's the questions I haven't asked my wife… did she get hot flushes before she had… the treatment… I mean I never… you know, but I don't know whether women get hot flushes… you know… if they're not on Zoladex or hormone implants so you'd think oh right that… that's a question I'll ask her when I get home today… I never thought of that one… but as I say I never had any hot flushes until this treatment.

I: How does your wife react to when you have a flush?

P: She laughs at it now, she goes now you can see what I've put up with all these years, you know… so err… and she goes look, it's nothing to fear… you know erm… but I said to her no I said you haven't got 'em… and she goes no but I've had 'em so I can relate to what they're like…

I: Yeah… and when she says that, how does that make you feel?

P: Guilty I feel…

I: Yeah? ….And why do you feel guilty?

P: Oh because I've taken the mickey out of her all those years thinking it was… erm… not that she was putting it on, but exaggerating with the flushes…

I: Mmmm.

P: And I know absolutely definitely now that she wasn't exaggerating… really that was quite bad on my part… you know.

I: Does she do anything to help you with your flushes?

P: No she just says sit down and relax… you know… if she tells me that I normally do you know, 'cause I like to do the cooking indoors, so if I'm doing the cooking then… you know you think oh you're over a hot stove you know, so it's quite hot… so you could say to yourself oh it's the cooking that's making me… but it's not it's a

different feeling CE all together, it's an internal feeling as opposed to laying in the sun and being hot, it's totally different all together.

I: And I know you've mentioned some things that you think affect your flushes like you mentioned the weather, do you think there's anything else that affects them?

P: Well… I can't think of… yeah perhaps if um… when I'm doing the gardening, if I'm sort of… not so much doing the mowing the lawn you know just pushing the mower up and down no but if I'm sort of on my hands and knees, you know with your head down to the ground and you're weeding like that...

I: Yeah.

P: I've had that a couple of times come on um… with me head down… you know like you get a bit of blood pressure like that can't you so… but I've only ever had that two or three times I suppose…

I: Two or three times that's happened?

P: Mmm yeah, that's all.

I: And what about like things that you eat or you drink or anything like that, do they affect them?

P: I've not been able to attribute anything… to that you know… uh I mean because I haven't altered my diet at all from before the treatment you know… not at all.

I: And I know before you said that maybe worrying about it in that first one that you had, could have made it go on for longer-

P: I'm sure it did.

I: Do you think that there are any states of mind you are in that could make them worse?

P: I think that initially when they tell you that you've got cancer, the first things that goes through your head is I'm going to die you know and you then… the second thing is… um… you think to yourself… how long… have I got you know and then… I would say probably after… a week or two of feeling sorry for yourself… you know… you start to put it together and cope with it what… I know we're all different but in life situation, start to cope with it… but it's always at the back of your mind, you cannot get rid of it and some days you think about it more… and then you go a week or two and it doesn't even go through your head, you can occupy your mind… you sit there watching the television, fine it doesn't go through your head because you're concentrating on something or if you're reading a book, the book's taking your mind up… but if you're doing nothing whatsoever… you know… you tend to

worry you know… and I do believe that worry can bring it on to ya you know… I really do.

I: Mmm… and I know that you said in the early days when it affected your life a bit more, the flushes, because you didn't know why they were happening or what they were…

P: No…no.

I: Were you feeling more worried then?

P: Quite anxious.

I: And did you feel that that came on more during that time or not?

P: I think they come on erm a bit more because of the anxiety you know seemed to bring it on.

I: Okay…and do you think that there are any other states of mind, like moods or anything like that, that can bring them on?

P: No… no… I do know from this treatment though that err… I've found that I've got a bit more aggressive than I was before err… never normally like that at all but now with the grandchildren if they come up or when they do come up and you know the three of them are all shouting at each other you know I would normally just ignore it and now I'll shout out shut the bloody noise up sort of thing… and then as soon I've said it I realise that, you idiot what d'you say that for you know… so err I'm trying to cope with that one in actual fact…I mean it hasn't affect me you know um… I think I've been rude a few times in the shops though to people….you know assistants you know… you know… and I have apologised though I must say that I have apologised because err but um…I'm starting to cope a bit better with that now though because um, I think I'm coping with it a bit better because I realise what I'm now doing… you know…

I: Mmm… yeah, yeah.

P: I think my wife helps me with this though CE by saying, are you listening to yourself?

I: Mmm… okay, and I suppose the other thing I wanted to ask is so do you think your flushes affect anything that you do, and this could be in the past as well when you first got them, so is there anything that you avoid doing because of the flushes or does it affect you in that way?

P: I'm trying to think… well apart from it can stop you in your tracks for a few… couple of minutes or so you know… depending on what you're doing you know… I mean if you was on the station sort of thing standing waiting for the train just to

pull in and you got an hot flush then you know, which has happened to me, I've stepped back…I've gone back two paces you know… 'cause you think to yourself hang on… am I gonna faint with it or something like that… I've had them a couple of times thinking…when it's been an issue in the early stages, is this what happens when you're gonna faint you know you say to yourself… 'cause you don't know what's what… I haven't fainted on any trains (laughs) you know.

I: Yeah, yeah… alright then and then you've told me about when they started, your flushes, when-what time period was that, when did they start?

P: I would say… about a month after the first injection.

I: When was that?

P: That was December last year… I think… it was either the end of December or January the 4th or 5th, somewhere around that period you know.

I: Yeah and do you think they are any different, comparing then and now, are they any different the flushes?

P: No only that they've eased up quite a lot… as I said initially it was a longer period that the flush would last… I mean I've had flushes that come on me you know for…thirty seconds you know… and then another time it seems to just linger on you know… and there isn't anything you can do, I've gone out and got a…a cold flannel and put it across your forehead and around your neck… but it's not that type of… heat you know it's not that type of thing CE… it's like if you could get the flannel inside your body… yeah.

I: What other types of stuff have you tried like that? So you said you put a cold flannel-

P: Nothing other than that I haven't tried anything other than that…

I: And do you get them at night?

P: But that didn't work.

I: That didn't work?

P: Nah… I've only had it a couple of times in bed you know.

I: So they don't affect you as much when you're in bed?

P: No, no… my wife said that she… used to get them quite often in bed but I can't say I have.

I: And how do you think you're flushes have affected how you see yourself or have they affected how you see yourself?

P: Um… I've adjusted myself… by slowing down… actually slowing my body down in virtually everything I do… um… if I do the garden I would crack round with the lawnmower, bang, crash, wallop, done, finished… you know I think, you know I'll take my time on it, you know, do the weeding you know and I think I'll do halve of them today then you know… uh… I wouldn't now run… to get the bus, I'd say uh hang on there's another bus sort of thing… an old guy told me that once… in Malta… I was running for the bus and I missed it and he was sitting on a chicken box you know with a couple of chickens in…alright and uh elderly very elderly gentleman, spoke perfect English though and uh I went oh bugger that or a bit worse than that (laughs) and uh I said I wanted to get that bus, so then he said why are you in a hurry he said there's always another bus, you're life's too short to run for a bus… I've always remembered that and because of the treatment and flushes and things like that I don't bother now, with the train and that I just look at it, well I'll get the next one then… and if I'm coming for a meeting like today with you… and I've missed that train, I'll ring you up and say sorry CE I've missed that train, apologise and that's it.

I: Mmm and do you think it's affected the way you see yourself in any other way?

P: …I don't know whether it's the treatment, flushes or what, I just feel… I want to be closer to people now… I don't know if you can understand that, you know I just feel like I want to be closer attached to people… I don't just want to say hello and goodbye sort of thing you know… certainly with the grandchildren more than anybody... I think that's because you're thinking… you'd like to see them grow up and get married and so on… I've got an almighty flush come on now (laughs)…

I: Oh have you?

P: You know and that's a… or if anything like that brings it on… that your mind's thinking of things like that, like caring and stuff like that… you know and uh… very peculiar… as I say you don't know when these are gonna come on, I mean I could sit here and talk to you and I've got one and it… but you… I didn't know that was gonna come on you know it's just… and it's not the room or anything like that because I can actually tell the difference between I mean I sat out in the sun last week it was red hot wasn't it you know and that is absolutely totally different… nothing like it whatsoever, a hot flush you know…

I: So… um-

P: As I'm talking to you know you can feel the hot flush subsiding, you can feel it going from here, going away…

I: When it goes away is it similar to the way it came?

P: It's a… no it drifts… it sort of drifts away.

I: Yeah, yeah and you're sort of gesturing downwards so is it, so you know when it comes you said it kind of goes upwards-

P: Yeah, yeah… up… yep.

I: And when it goes, it goes down?

P: This thing it just comes down and drifts away… it's as if it's like your soul… you know, very peculiar, you know…

I: Mmm… okay… and now how much do you think your flushes affect you know, so you've spoken about before, how much do you think they affect you now? Or how much do you think about them now? Sorry.

P: I don't actually think about them at all now CE, they… I now, I accept that they're gonna come on at any given time you know… and just accept it and um… and do what my wife suggests, like wherever you are just sit down and chill out for a few minutes until it subsides… sometimes you know if you're walking along, you just carry on walking with it and put up with it… I've never once had it yet though… driving the car, not once ever!

I: Driving… does that surprise you?

P: Well yeah! I mean because it comes on at any given time I mean I get on the train you get it, get on the bus and I've had it and walking I get it… but I've never had it driving the car…not once…

I: Why do you think that might be?

P: Not a clue… I mean I can't see it's anything to do with concentration you know err… because I've sat reading a book and it's just come on you know…

I: What are you normally like when you're driving the car? How are you… driving?

P: Normally calm as can be but started to be aggressive… I mean normally someone cuts across me I just go, bloody idiot, now I go you… so and so and so and so and shout… so and I don't know whether any of these is treatment… or… err hot flushes or it's the Zoladex or anything like that… I'm due for an appointment in December up here to see JK and I'm gonna say to her a couple of these things that I… I mean alright I'm controlling this a lot better now this aggression but um… is that a normal part of the treatment, should you get aggressive or is it you being annoyed with your own body that's causing it… you know…

I: Yeah… and so… I know you've thought about some of the things that have worked and haven't worked when you've tried stuff so can you talk me through some of the things that you've tried that have worked and haven't worked?

P: Well as I say I've tried the flannel you know… I even tried going down the gym to see if exercise would help… (laughs) that didn't make a difference apart from make me more tired you know… just trying to think… oh I've tried altering the diet slightly… that didn't make any difference whatsoever.

I: What did you do to alter it?

P: Well I went on the salads you know… and uh not being a… a rabbit lover (laughs) or that type of food right I'll go down this after a week you know… uh it didn't make any difference you know, you know… in actual fact I think I had more that particular week than previously! Whether that was because I changed the diet… I don't know you know…if I can remember correctly, I think I had about four that week when I changed the diet, but whether that was a good thing or a bad thing and I perhaps maybe should I have carried on with it, should I have not, I don't know…you know.

I: Mmm… so you seemed to have more of them than usual?

P: Yeah whether that was pure coincidence who knows… I mean I went back to the old diet… which I enjoyed.

I: What do you try when you're out and about… and you're hot flushes start?

P: Oh when you're out and about I mean I always go shopping with my wife and my daughter and it's… they always take the mick, they only take me so I pay for the food CE! You know and invariably everything is now fast-food places isn't it you know… and uh we'll go to Bluewater we'll go to Lakeside and it's uh… we'll go into Macdonald's or… not Burger King 'cause I'm not a lover of that but it'll be somewhere like that… um… but if we go to Lakeside… I always find Lakeside's more down-to-earth for us sort of people… you know the shopping's not all designer and there is a good variation of food there… total variation from fish and chips to sausage in mash to pie and mash you know to Thai food, Indian food and so on… there's such a variation you know…

I: And when you're out and about like that, how would you, what would you try to do to manage a flush if you had on when you were out and about like that?

P:…I'd just actually carry on with it… now I have, I've just carried on with it now before I used to stop but now I just… stop for a second or two right, take a deep breath and carry on.

I: What did you do before?

P: I'd just stop for two, three, five minutes, you know… wherever I was I mean if I was down the high street and I wasn't in a shop I wouldn't sit on the kerb, I'd just lean against the window of Marks and Spencer's or something like that, I wouldn't sit down you know… unless… there was… like when you go down the XXXX high

street over on the left-hand side there's two or three seats, now if I was on that side, I would make a beeline to go and sit down there.

I: But you wouldn't sit down normally though if there weren't seats available?

P: No, no… I think I'd be too embarrassed to sit on the floor or sit on the kerb.

I: Why's that? What goes through your mind?

P: I don't know I think everybody'd be looking at you and you know thinking what's he doing sitting down there on the floor… you know… although when I was younger I mean I (laughs) sat on a kerb many a time, they've just ignored it...

I: Yeah, yeah.

P: But as I say as you get older you… you alter slightly you know…

I: And are you, do you kind of wipe your brow or wipe yourself down with anything? Do you carry anything to wipe yourself down?

P: No I always go like this, take me glasses off and go like that and then I go cor, like that… all sort of rub your face down you know…

I: And do you ever remove clothes or anything like that?

P: I've done that in actual fact I've tried that CE in actual fact indoors… whereby I've said to my wife cor if you've got that heating on and she goes no I don't, oh I'm terribly hot and I'm like this you know, take this off… I've got a vest on today but um if I've got one on indoors I go I've got to take this off as well you know… uh it don't make any difference… it doesn't.

I: Mmm.

P: Yeah it doesn't take it away at all.

I: And you do that indoors, would you do that outdoors, like take stuff off?

P: If I was outdoors and I erm had me coat on and I was going like that I don't, I wouldn't take it off and show me chest sort of thing go like that you know but I'd certainly take the top coat off like that… but in saying that it doesn't seem to make any difference with it.

I: Do you think there's anything about your background or the way you've been brought up or anything like that that helps you with your flushes or that affects the way you experience them?

P: No I mean… I actually worked for… years as a lorry driver um long distance lorry driver erm… and that, that's a lonely job, you know 'cause you're driving up the

north, driving down the south, down the west, wherever you are you know, alright you go into café's and you meet another driver and you have a little chat but you're always on your own and then prior to that I worked for the err water board as a jointer and that was out in all weather's as well you know… so up until… I was… about thirty-eight… I always worked outside and then after that I went to work for the bank as a porter erm… the foreman died a month after I started, they gave me his job… six months after the supervisor died and they gave me his job and… and my life changed in 1993 when the IRA … blew up the city and there was sixty-three of us in the building when it blew up… that day and my life changed then… and I'd never cried from the age of being at school until… the day I walked up my footpath and saw my daughter and my wife standing in the door, that's the only time I cried that much, horrible feeling ever… the rage that you had, that you'd lost your job… in actual fact you didn't lose your job what they did they put you into terrible jobs, really bad jobs hoping that you would pack up… but we had a gentleman's agreement with them that anybody that was in the blast would be kept on and they broke their work you know about eight years after that… so I did about twenty years with them you know… and uh 'cause we bought another bank out… well that definitely changed my life… and then one of the guys who got laid off with me… we both got laid off at Christmas… oh he got laid off in November and I got laid off in Christmas and he rung me up on Christmas eve and said I've got a job… so I said oh well done, so he said I've got a job here for you for six weeks if you want it in the city… so I said doing what, he said drafting some contracts, so I said that'll do me I can look for a job then… so he said after Christmas come up… went up there and uh they had three manager's there just starting up, xxx bank, German bank you know, they had twenty-five staff, a CEO, a secretary, a treasurer and these other three mangers that I was under… when I got there I said so what do you want me to start, is there somewhere where I can work to do these contracts? He said oh make some tea, I said oh fine… then the postman come, he said do us a favour and run the mail round… right alright… so I got to know everybody didn't I?

I: Yeah.

P: And then they was fifty people… there was fifty teas… then there was a hundred people, so I couldn't make the teas could I? Then the post was going like this and like this… and I said I can't cope with this… well you know how to make a mail room, I went yeah… I didn't know, I rung the Royal Mail up, they sent someone down (laughs) did it all for me and then I came along on the Wednesday and the guy said um… your manager's sacked… I said what for? You don't want to know… I found out…he was messing round with the CEO's wife, he found out and so they sacked him…the other bloke, who got me the job there, six weeks later he got the sack… for fiddling… a year later the other guy got the sack but in between that time he found out what my previous job was and he brought me in the office with him… he

was an older manager, he got the sack for fiddling… so anyway I carried on and I was going home one night and I got a phone call on me mobile… and um… they said is that you XXXX (name), so I said who's that? He said XXXX, that was the CEO… I thought what's he ringing me for you know… and uh really boosted my confidence then…really… he changed my life that night again… for the better you know and um…he said uh how's things going in London? So I thought oh he must be in Frankfurt… I said oh they're alright I said the one thing I have done I said I got morale back up and working I said so that's a good start for us all… so I said everything's working okay… he said great, he said keep the good work up… I went in Friday morning, his secretary called me upstairs… so she said you get a phone call last night? I said yeah around six o'clock… so she said do you know what it was? I went no, she said he was ringing you from Tokyo…

I: Oh…

P: I said oh, she said d'you know what time that was out there, I said no, about four o'clock in the morning…I said and he wanted to talk to me, I said I'm down here and he's up there, and what a super guy… never known a man like him and uh… he went and started his own company up over at XXXX and uh I stayed there another… three years and then I thought… I'm old enough to retire now so I packed it in… I thought I don't want to work 'til I'm sixty-five so I packed up when I was sixty-one…

I: Yeah… yeah… and with these experiences… is there anything about them that helps you now to manage your flushes and cope with them?

P: No not really CE… I can't think anything there what would have helped you know… I mean I've been through some traumas you know… I mean everybody that was in that blast was compelled by the bank to go and see a psychiatrist which we did… uh up XXXX… you know… and they'd hypnotise you and all that you know and uh… I actually used to put meself under hypnosis with 'em…

I: You used to do that?

P: Yeah, yeah… quite easily you know and uh… he used to say I'm amazed you can do that… I've got my head in a position you know and I'd have to work into and get myself into it and he'd ask me everything and I used to tell him the same story every time… I'm in a tunnel with a white light at the end and it's all skeletons looking down on me walking through it you know… and whether that was that the building had blown up, we were walking through it you know and we were trying to get out to the daylight you know… who knows…

I: Yeah.

P: And that, that went on for… I can't remember how many weeks that went on for… you know… must have been about a couple of months… and then I… he said to

me how are you feeling, I said look… I said I don't think you're help is really progressing me any further than we are at the moment, I'm coping quite well you know… I'm not thinking of the blast anymore, the only thing I couldn't do, I wouldn't have been able to walk in this room… too claustrophobic…when they first put us all together and they had a massive room uh… on the river and they put us all in it and brought a psychiatrist in it and every single person, girls, men, women, all walked out…every single one of them had the same feeling…you know and I normally before that, wouldn't have worried…but it was just that there was only the one door you  came in and there was only the one escape route out and it wasn't good enough for ya so… I mean you've got a door behind you but it's probably like a brook cupboard sort of thing…so…

I: Yeah so something you couldn't get out of… um… just to ask as well thinking about your flushes, how-

P: I mean that flush has gone off of me now.

I: Completely gone?

P: Yep, yeah, yeah.

I: How long do you think your flushes might go on for?

P: I would think that as long as I'm taking, not taking, having the Zoladex injection for hormones, I believe that I will always have it… you know, that's my personal opinion… and I think that all I can do is cope with it as best I can… because as you rightly said there isn't any known tablet that you can take that will say here XXXX (name) take the Paracetamol and that will get rid of it… it doesn't work that way CE does it, you know so… hopefully when all this that you're doing is all put together, it might be something there that someone will find out there's a trigger point somewhere… that none of us are aware of, you know, or there might be something just in the Zoladex that someone will come up with and add something to it that stops it… but you can after a period of time cope with it… you know…it's something you can live with you know… it's not something that you want, you certainly don't want it but it's something you can live with… as uncomfortable as it is at times and it is uncomfortable.

I: Yeah… I'm going to ask you to do something for me, so I've got just a sentence completion task here, so I'm going to just say them and then I want you to try to complete the sentence for me so… during a hot flush… I am…

P: Overcome, overcome…

I: Okay… anything else?

P: No… not really no, no…

I: During a hot flush, other people see me as…

P: That there's something wrong with me you know… I mean uh people say to ya, is there something wrong with ya you know… I mean 'cause you're like this you know, you know… you're wiping your brow and people are saying are you okay, are you alright and I go no don't worry it's only a flush… and they go oh… alright… and just like that… (reads aloud) during a night sweat… just to say I haven't had that very often and all I've done with that is uh I just get up you know… there's nothing I can really do with that…

I: And how do you… so during a night sweat I am….

P: It's just uncomfortable.

I: And during a night sweat other people would see me as…

P: Well what I would say is a nuisance (laughs) you know a nuisance.

I: A nuisance…

P: Yeah…but as I say CE, I haven't had that (night sweats) a lot you know… I haven't had that a lot.

I: And just thinking about how other people would see you, I know you said they would think something was wrong with you, what do you think they would-

P: Well 'cause you're going, you're taking your glasses off and you're going (exhales) crikey like that you know (exhales) you know… that's when people say are you okay XXXX (name) you know.

I: What do you think they might think is happening?

P: Err… I don't think I really take any note of that side of it, you're just more concerned with yourself than what other people think you know… I mean I take more notice of my wife than anybody else I mean… if we've been out for a meal and it's come up and I'm overcome a bit like that she goes just relax, you know, just relax.

I: Alright and then the last bit I just wanted to ask you a bit about, you've already spoken about what you feel causes your flushes, what do you so are you receiving any other treatment for managing the flushes?

P: No, none whatsoever, I don't even know if there is anything for it you know… it's just something that I've accepted I've got you know and put up with it really you know… but seeing that I've met you today, it might be worth speaking to JK or LF when I see them in… when do I see them… in December I think… no, is it… must be, must be December I think, yeah I think I've got the injection…no it's not, so it's

October, November… yeah it'll be December yeah, when I'll be seeing them… so I might bring up a few questions as to is there… any tablets you can take, is there any treatment, is there any therapy you know…

I: So you, at the moment it sounds like you don't know of any other treatments out there?

P: No, no and no one has informed me that there is.

I: Okay… so there's a question that I asked on this form, would you be interested if there were other treatments out there?

P: As long as it didn't affect the treatment that I'm having for this prostate cancer, I'd certainly look into it… you know… I'm not so sure I would want to be like a friend of mine who's done two or three times up at XXXX (hospital) being a guinea pig and he's been in hospital for a couple of weeks…

I: Yeah, on medication?

P: Yeah and they've done all that and you know, he got well-paid for it you know well-paid but uh I don't know if I want to be a guinea pig at my age.

I: Yeah, yeah… well I suppose there is-

P: You've got to find out somehow but… but it's not the sort of thing that you would say well I'll go and sit in bed in a hospital for a couple of weeks and you sit there for a week and you think… I've only had one flush today you know, next day, next day, next day you haven't had one and then in two weeks you might have had four flushes! You know I mean, I don't know how you'd prove anything by that.

I: It is quite-

P: The only thing I could think of with the technology that is about now was if you was in hospital for a few days and a flush came over you and you had a load of leads over you and it monitored the change in your body, something like that… but I certainly wouldn't want to go onto any type of medication, not without really looking into it.

I: So on here you said if you did have a treatment preference you would chose medication…

P: Yeah I thought about that afterwards you know but only if I was guaranteed that look, you've taken your two Paracetamol's and that will get, that will really help you with it XXXX (name) yeah…

I: Okay… the other options as well so just thinking about so attending a group to manage-

P: I don't think that would help at all, talking about it.

I: And then a self-help guide to manage the flushes and sweats, what do you think of those two options?

P: That, that might… be worth… that… yeah, yeah…

I: And just thinking about the self-help type of thing, if you had a preference would you, so if there was a CD or consultation with somebody, talking to somebody or if there was just a booklet or a guide, would you have a preference for any of those things?

P: I think you could have a CD of it, like we're talking now and if we were videoed here now and a guy's indoors worrying about it and he can see you and I talking about it and think yeah that guy's got what I've got, I get it like that, you know… I think that would be quite good.

I: Okay and-

P: And very interesting and you could adapt yourself from it I would think, you know.

I: The other thing I wanted to ask was if you were to consult with someone and see someone, talk about the flushes and get advice about them, would you prefer if it was a man or a woman, would you have a preference?

P: Oh no, no, not at all, no… none whatsoever, no… I mean if you can go and have radiotherapy and they lift your clothes up and see your private parts and things like that uh… I mean it's not as if they're sort of peering at you like that… I mean one guy was up there and he said I think this is quite degrading these females looking at your private parts and we said to him, they're not looking at ya, they just got to put the paper across there you know, you know to do what they've got to do… he went well I don't see that…

I: Everybody's a bit different I suppose.

P: Yeah… they just said like lower the bed, pull your uh… housecoat up and the girls put the paper over you and they chatted to you as they do you know… they're superb.

I: Right well I was going to say that's most of the stuff I wanted to ask you, we've covered quite a lot, is there anything that we haven't covered yet that you'd like to say or you'd like to ask?

P: Well I thought this was uh… quite good right… erm… it's a pity that it had to come from and be informed from a friend than… like meself… that because you're having this treatment and that the doctors would be aware that you do get hot flushes,

they would put all the names forward to say right give all these names to CE and get her to ring up Bill, Harry, Charlie, so and so, so and so… it don't quite work this way does it?

I: Well that's exactly what I've been doing at the moment and that's how I contacted XXXX [Pp018] because he attended clinic where I've been going to lots of clinics and things but because it's quite new and I think XXXX [Pp018] just got there just before I probably got to you because I would have got your name.

P: Well it doesn't matter whether it was it, because XXXX [Pp018, friend] and I are quite close now.

I: But it is yeah, we are trying to do it in clinic because now more of the doctors know, there are leaflets up and so-

P: Mmm yeah, I think it helps though, it does help though in actual fact when this like, as I said to you we was XXXX [Pp018, friend], errr… XXXX and XXXX (two other friends) together so we all speak about it you know so if one said here I'm up tomorrow with CE, what's that for, oh I was up talking about this… oh ask her if she can give me a bell, or do you want me to put your name forward XXXX [Pp018, friend] and so on like that… you know… 'cause it's nice to talk within a little group… the problem is having a group like this that's talking about it and I'll probably sound blokey… some of them are real miserable bastards, really are you know… and we've been up there and tried to help and they don't want to know, you know, really don't… but when you're in a, you've built up a relationship with these people and you're on the phone and uh it's like how you doing oh alright mate, going away next week with the wife, oh where you going, Portugal, oh have a nice time, how you feeling, oh still a bit tired and oh these bloody hot sweats are a pain the bum…you know… you know… and you talk about it between you that way…so like I said if you had a CD to just sit there plonk it in you know and… and you think you know… you've got to have a CD of a forum though, of say like four guys like us were willing to sit in a group with a person like yourself and talk about it… and not be embarrassed that you're being videoed you know… erm… and then it can go to the various people… because I wasn't told anywhere along the line from the beginning that you could get hot flushes… I was told about the breasts…I mean they're not quite as (laughs)… but they are there you know uh and the waist they told me about that.

I: But you weren't told about the hot flushes?

P: No not hot flushes no, no.

I: Do you think that would have made a difference for you… if you'd known?

P: I think it might have helped…but… to be expecting them… it might have helped CE, it might well have helped… yeah.

I: And then I was going to ask you a bit about how you think your flushes have been managed by people around you including professionals?

P: Um… my GP is an absolute superb doctor, really is you know and each time I've been there to see him, he says to me… how you coping, right, I've got you're records here, because it's all computerised now…I've got 'em there, some good results X right so I said oh right that's very much… then he goes now I told ya, don't start worrying or anything like that, if you're going to die, you're going to die of something else, so let's get this out of your head now, have a normal life, get with your family, children, go away on holiday and all that you know um… and I've only spoken to him once about the hot flushes and that's oh you know just a quick walk in, walk out sort of thing and he goes… you're going to get them you know… but he hasn't said to me and I haven't to be fair to him, I haven't been back to him you know 'cause I think it's just one of these things that… well I presume that you just have to accept… I don't know if there is or is there any medication at the moment CE?

I: Well not as far as I am aware at the moment but the best people to ask about anything like that are JK and LF, they'll know more about what's out there medically.

P: Ask those… yeah… yeah… what I might do is… start a log now, between now and when I see then… like today's what's today, sixth, sixth today… right… meeting in Guy's... approximately eleven o 'clock, hot flush, lasted about five minutes… you know… and then say like this is what it's looking like, is there anything you can do for this or if now, right I'll just adjust meself to it, which I am doing anyway.

I: Yeah… so that is everything that I wanted to ask so do you feel that the interview has captured your experiences of your hot flushes and night sweats?

P: Yeah, yeah I think it's been very good in actual fact… you can get it off your chest you know…I haven't had anybody to really relate to with it you know… uh it's not the sort of thing, you can't go into your GP and sit there for an hour with him you know, it wouldn't be fair to all the people that need to see a doctor you know and uh I don't think it's be far to LF and JK as well for an hour because… you know as well as I do it's like a freight train going through that department you know… it's non-stop, non-stop… you know…so uh but I think this is quite good because this can, when it's finalised over however long a period this needs to be done you know uh… the more people you get to do it the better it will be because you'll be able to evaluate your data and go oh this group of guys are in their sixties, they're getting more than the guys that are in their late fifties and so on and so on…

I: Mmm mmm.

P: Right this guy eats a banana everyday, he controls it to once a week… I mean you know I'm just making this up CE but you know, you know…

I: Yeah but you're, that's exactly the goal… and I wanted to ask you are there any answers you'd like to change or take out?

P: No, no… the only one I was talking about was the medication one, you know… uh… um in saying that you know but I do think you know I wouldn't want to change anything I've said here today uh, the only thing I would reiterate on is that when it's finalised it might be good to have that CD available to someone…even if you had to pay a small nominal amount for it you know… that went to… I don't know Macmillan's or…

I: Yeah, the prostate cancer charity?

P: Prostate yeah… whatever you know…

I: Okay well thinking about that then… I'll stop the tape.

Appendix L: Interview transcript for Pp032

**Transcript: Pp032 (rec 19)**

I: So the first thing I would like to ask you is, if you could tell me a little bit about your hot flushes and your night sweats in your own words.

P: Well when it started first it was very very um uncomfortable, the uh hot flush, I'll explain it, it's just as if something just I could tell if it is coming… I could feel like a heat and something like your body's not yours for a couple of seconds and then you just started to sweat out the hot flush… so um as I said I can tell when it is coming I know um… it's only sometimes where you are you're not prepared so you're just sort of a bit embarrassed yeah but it's something that I have to life with, but the sweating that is very very bad… a few years ago it's coming down but sometimes it's so bad that I have to get up and change my night clothes like three times a night.

I: Three times a night?

P: Yeah sometimes, mostly two but sometimes three and the uh difficulty about it is, am I going to fast?

I: No no go ahead.

P: The difficulty about it is that sometimes when it's sometimes it's stuck to your body and I have to pull pull and I can't get it off and I have to ask my wife can you take it off… because it was stuck to your body and then it can get a bit annoying.

I: Mmm.

P: And um I've used a fan, but the fan… it was a help for a short while and then after a while you can easily catch cold with it so I used it um sparingly.

I: So you use if for a short while and then you get a bit cold?

P: Yeah yeah just to calm me down but… the fan really doesn't help, it doesn't stop the sweating but it just helps you to feel a bit more relaxed.

I: Okay and when did your flushes start, so when did they begin in the first place?

P: It's hard for me to remember the time because I know it's just after I was diagnosed, I started to get the um hormone injection and then the flushes start because I was enquiring about it and there was nothing they could do, for a short while they put me on some tablets, I just forgot the name of it now but yeah short, so the doctors mentioned to me that um you know maybe one out of twenty would

come back and say it helped, they asked me to just try it, I tried it and it didn't help, it didn't help at all so I went back to the doctor and explained so he stopped it.

I: Okay, do you remember how long you were on it for?

P: What the tablets?

I: Yeah.

P: Well it wasn't for a long period, I just can't remember but it's not all that long because um… I can't remember the exact time but not for a long period because I was aware that it wasn't helping and the doctor explained before that he doubted it but just try it…

I: Yeah and when you say you know it wasn't a long period, do you think it was weeks or do you think it was months?

P: No it was just type of like six, six weeks or so until I go back and see him, between six to eight weeks… but that's been the period of time that I usually go back to him again to come and sit down so… short time period (laughs).

I: Yeah so when you took them and they didn't work for you, how did you feel when they didn't work?

P: Well I just said now I just went back to the doctor and I explained to the doctor and as I said before he said he wasn't sure that it would work so they said I would have just continued until it died down the sweating… but um one of the things too that I should mention is to you now because it's very important, I think I'm caught out with sweating because I'm diabetic, I have diabetes so if my um, which I've proven recently, if my diabetes is not completely under control to a certain reading I find myself will sweat, so that was helping at the first time yeah… so my diabetes is under control now, the sweating at night it will be about two of three times but I… but just recently I find every morning before I got up, I would start sweating and even when I checked my um diabetes, it's been alright so it just means I'm still sweating from um prostrate problem…

I: Yeah… mmm, and so I know you said you started with the sweats as soon as you were diagnosed and you started taking the injections-

P: Yeah.

I: -do you remember when you were diagnosed, how long ago that was?

P: Yes… November coming it's five years, I can't remember the date but I know it's November coming it's five year, sometime in November I can't remember the date but I know it's November.

I: And do you remember how long after your diagnosis that you started the injections?

P: I think it's something….you know what I'm not going to remember God… no I think it started quickly after I was diagnosed because, because it was in the blood, they didn't hesitate, which I appreciate very much because without it would, I went to a (RESEARCH TRIAL), you know what they call it (RESEARCH TRIAL) yeah I went to a (RESEARCH TRIAL) so I was given quickly after each other the um… injection and um the different tablets, I didn't count the different tablets because I don't think it was necessary but I did different tablets that whole time but everything was under, just one after the other so it wasn't a long period of time… and I was being checked regularly just to make sure that they are working.

I: And then do you remember how soon after your injections that the flushes started, do you remember that?

P: No, I can't remember… but I, I asked the doctor and I can remember they um said to me um it's the um hormone injection that causes it but I have to continue taking it, I have to continue it's because according to my sickness I have to continue taking it I have to just bear with it and as they explained it, it won't go by now but it will kind of ease down… and they're right because right now it's coming now but not as regular as before.

I: Okay, so you feel like it's changed over time then, how often you have them?

P: Yes, yes it does yes it does.

I: When you first had your first hot flush or in the early days, what were your initial reactions, how did you, what did you think was happening?

P: (Laughs) I like that question (laughs) well let me tell you and speak to you the best way… you wonder what is taking part in your body what is happening, is it um… is it gone too far, can they help… because that has been my experience of it before so it's a bit of a puzzle and you're, we call it puzzled or wondering what is going to happen if so how far has it gone, can they help me whatever I'm going to go through and all this, all these things that come into your mind they start there first… because the hot flushes was as I said, it's you feel scared when it's coming on.

I: And did you know what they were when they first started?

P: No, I didn't know until I went to the doctor and explained to him what I'm having and then he told me that um it's the injection and they're at the most part of it but I have to do it… hormone injection.

I: So you said you weren't really sure what was going on in your body, when it first started?

P: No, No.

I: Um what kind of emotions or feelings did you experience around that time?

P: Uh… I'm coming just give me a second to think remember when I came in I explained it… as I tried to say it is a bit frightful, it's a bit frightful… because not knowing, not having had this thing before and not knowing what, how badly it's affecting you, where it reach or anything so it's a bit frightful and um… yeah I would say it's a little bit frightful and a bit stressed a little bit stressed everything not knowing, it caused a little stress when not knowing… but after the doctor explained, I am one who just have to accept things as it is knowing that prior a doctor really can only help you so I just continued to do praying and everything but I just accept it then, so by accepting it I'm telling you the truth I don't sit back and just fretting or anything, I get on and do everything that I have to do… just as if it's not there but when it comes on I feel it, but otherwise I pretend it's not there…

I: And I know you said you kind of just accept it and carry on-

P: Yeah.

I: -and I know you said you pray and everything as well-

P: Yeah, yeah I'm a Christian.

I: What type of things would you pray for when you were thinking about it?

P: This is something I want to say because um the last time, I can tell you this quickly, the last time around September… I don't really know but I think it was July, I went to the doctor and she told me that my PSA is rising and uh as I told you before I was on (RESEARCH TRIAL) and then I had to go to plan B now and I said to the consultant before I said how bad is it and she said oh it's not that bad but once it's moving they the doctor have got different stages they can help so I turned to her and I said well I know you can't help because of us all here but I have to believe that there's a God who hears and answers prayers and I'm going to pray and um two days before I went back to her, I'd, somebody took my blood test I think she can have it before if you know and I was surprised a day before, the same day I went, which I've never done before, in the evening the phone rang, can I speak to XXXX XXXX (name), I said speaking, they said XXXX (name) your PSA has dropped down and it's level… and as I said you just have to be grateful and pray and hope that God hears and answers my prayer and since then I've been back… and they say it keeps dropping down so instead of seeing me every month I see them three months now so what a joy what a job.

I: Yeah, yeah…

P: And I was so glad to see the impression of the um… the consultant expressed it on the phone, her gladness oh she was glad too she was, the female doctor, she was very excited 'I'm so glad for you that's why I'm ringing you now' because when I went in the morning I expected to have all the results the same evening, I thought she could take it up and ring me back that was very good so…

I: Yeah, so quite fast when telling you the results?

P: Yeah, yeah, yeah… I just went to church and I gave that um experiences ah it was good yeah.

I: Yeah, do you think that there's anything about your upbringing or your background that helps you to cope with your flushes and accept your flushes?

P: Uh-huh, a hundred per cent I believe in that, by the way I was brought up… it helped a lot, it helped a lot.

I: Mmm, can you tell me how… can you tell how a little bit about what about your background helps you accept your flushes?

P: Yeah… well Christianity is something that it's… maybe not everybody experiences it you know about whether there's a God and so when there's thing happen and my parents were Christian so things I did when I was going to elementary school, I usually prayed… ah no sickness and studying for me to pass my exam and things like that so coming and having this here now and at the back going to look… of Christianity behind me so when I was diagnosed that I had um… prostate cancer, I just kind of gave a smile and my doctor said, the doctor said to me, who diagnosed it, 'there's something about you I don't understand, your smile someone would start to cry', and when I went home, I told my wife… and she said I can't believe it, I said what, she said you don't look sad, you don't look, I thought you'd be coming crying and everything and my daughter said the same, I said why should I cry it's the irony, you've got to accept it, so that was it you know that was background…

I: Mm, yeah.

P: Even the doctor was surprised.

I: So for you it feels like when things happen, life with prostate cancer and with these flushes now, you're saying that you just accept it and carry on?

P: Mm-hm that is true I don't let it stop me from doing what I have to do, I just accept it and carry on because personally there's nothing I can do… so it's only the doctor that can help me and praying to God to, to trust the hands of the doctors or to give them more understanding that they can help so that is my belief and I strongly believe in that.

I: Mm.

P: And so far it seems to be helping me because, this five years now… I'm just as happy… when I go to church and everything my brothers and sisters say I can't believe it man, because they knew, I can't believe it then why are you so happy, why are you smiling for but why should I be sad… as you know fretting and worrying going to make it worse, I've been a diabetic and I have prostate cancer, that's two main things that you have to try and not to fret… or worry because fretting or stress could only cause those things to get worse, so I just try to keep away from being stressed.

I: Yeah… and I know you said you're diabetic as well and how do you think your diabetes has helped you to manage illness in the past then I suppose then?

P: Maybe, and I use the word maybe, that is that being diabetic has helped me to… to understand the cancer more or to um… just simple not worrying… because being a diabetic for so many years and going through this and that and everything and injections, I'm on insulin now so it helped me not to worry, it helped me not to worry because um it helps me a lot with my cancer… prevents from being worried… because many people when they are diabetic or especially on insulin, they're worried and think that it's the end of time, they'll soon die, they see that they are… but to me it never occurred to me that way at all, never… and I know as long as you stick to the diet and keep to the diet, you can still live for many many years, how many years have I got it now… eighteen years, sixteen, eighteen years, yeah, so…

I: Okay… and can you tell me about um a recent hot flush that you've had?

P: Right, the recent hot flushes that I've got and I'm going to be honest with you, they are not as severe as when they started first… when it started first it would take um like a few seconds befo-I know it's coming, you could feel it, but now I can feel it but it's not as severe as before and uh like to my wife I would say mm it's coming on and before I couldn't even say it's coming on, I could feel it first started to, hot flushes, but before it took a long period of time, it kind of works through your body, your body feels like… it's not yours, something is in there working and then you realise what it is but you feel as if something is working within, inside you.

I: Mm… so now it seems to come on faster-

P: Faster, but not-

I: -but before it took longer?

P: Yeah, it took longer.

I: Yeah, and what happens in your body like what, can you describe exactly how you feel, like what happens when you have one?

P: That's what I was trying to say before, you feel as if, something is working in your body that is not yours, it's just kind of tightness and like a short breath and um heat, most about you but this heat you feel this heat in your body… yeah it's like a short wind and it was tightened up like an air hole… and your breath is like it's a bit short breathed at the time until when it calms down then you start to breath properly but it's the tightness of it you understand me.

I: Okay, and where does it first start in your body, that you're aware about?

P: I could feel it in my abdomen there… yeah that's where the feeling started to come from… but mostly when it started it's coming from the head, when it started, when it's first starting it comes from the head and the face down um mostly… and to around the neck.

I: And that was when it first started that happened?

P: Yeah.

I: And then now it's sort of spread to your abdomen and then works, and then when it starts in your abdomen does it move anywhere else?

P: Yeah it kind of comes up, it comes up, it hardly goes down… for it to go down um it used to be like sweat down there or anything now, it takes a long while but from here it comes up I could feel it.

I: Yeah… and what kind of things do you do to… what do you do, when you have a hot flush, what exactly do you do?

P: Relax… just to relax and sometimes you could go to the fan, now you know the fan won't be able to stop it but it helps with the feeling… it's a better feeling when you're by the fan but it won't stop it but it would feel better and you get the cool breeze and the fresh air, you feel better, more than if you wasn't beside the fan…

I: … And is there anything else that you do?

P: No, it's just one thing you have to make sure that you have um tissue nearby or your hanky, which is… normal things you have nearby you know… but um yeah as I already said to you just the embarrassment of it sometimes you're with family or friends and they say um 'why are you sweating? Are you sweating? I'm not sweating, is it hot?' and I say no no no I can't explain now but it has nothing to do with you and they say 'Well what is it then?' I say nothing to do with you… so there are some times when I go to different places, I was about to say that when I came here but I know you'll understand but sometimes my sweating is not fear or anything it's just that… it took place without telling anybody or the world I have no control… but it doesn't last that long sometimes now.

I: Yeah, so if friends and family are around you and they see you sweat, what do you think that they might be thinking?

P: Well I think some of them would realise that something is wrong but I'm not one whose going to tell everybody what sickness I've got, so mostly I would pick the easiest one and say well if could be the tablets for the diabetic I'm taking, diabetes I'm taking, I don't want to explain everything to everybody so I do that but who knows before would just hold on their head don't say anything, who doesn't would just wonder 'then what types of tablets?' I say I'm taking several tablets now and I can't go through that so they just stop it there and then most times I would make an excuse, just move away from where I was until it settles down and then I come back.

I: Mm, and I know that you said that you wouldn't tell them exactly what it was about, you know the prostate cancer or the injections, is there any reason why you wouldn't want to say or you wouldn't say what it is?

P: As I clearly said before I have a sickness because it's not something that I'm going to um be ashamed of, I say I steal and I go to prison and everything, no it's not something like that, sickness is sickness, you and I can have it at any time, we don't know, we haven't got control over it but not because of that you've got to tell everybody that um I have this and I have that and I have… no no it's just sometimes you just feel like keep it to yourself… I hope that explains it to you…

I: Yeah, yeah.

P: … And you know some people just take things and they just go and spread it without, telling others about it and they don't even know the right and everything so sometimes best not to let them know, just keep it… but it's not something you're going to hide forever because… as I'm saying this now, it's five years now and I realise and I know that in time to come in the future it will get worse, it is cancer and it will get worse, so when it comes I'm not going to worry because I come looking forward knowing that it will get worse but as it is there now I'm happy within… and then I may even die I don't die of cancer or something else but then I know as long as I live it will get worse, I'm getting older and um… how long they will be able to control it I don't know… one thing I'm glad for, I'm very glad for, it hasn't reached the bone, 'cause once it reach the bone I was told by different doctors that it's not the end of it but there is very little that they can do… and I've got friends who have got it and it reached the bone and I saw how they deteriorated, some died, some just about dying… but I was told by the doctor thank God he said it hasn't reached the bone because the lymphatic system so therefore then, so I'm not to worry, you can live for many many years.

I: Okay, good, good… and I know you mentioned um you know you say it's not fear or anything to other people if you have a sweat you know you say it's not fear or anything, what would make you say that?

P: I can't make, it's just stopping questions from being asked sometimes, too much questions being asked sometimes and coming and then it depends on where you are, like I'm coming here now and you see I'm just sweating, if you didn't understand you'd not probably try to open the window there and you'd say why is he, he's nervous, he's sweating and that's the thing and he's sweating… so sometimes I will just come in and as I said before I'll say please if you see I'm sweating don't be alarmed, take it as if it's something I'm used to and because I'm having tablets I can't explain everything to you now so if I'm if I'm sweating just ignore it, and it, then it stops them asking too much questions… and sometimes too much questions can make you feel embarrassed because you don't want to tell everybody everything so you know who you're just talking to… so if you can stop them before they ask any question it's better for me, yeah…

I: Yeah, mm… so do you think that your sweats that you have, do you think they affect how you feel when you're having one? How does it make you feel when you're having one, like other emotions?

P: Please explain that again, I get it clear.

I: Yeah sorry, so if you have a hot flush or a sweat, if you have one, how does it make you feel, so physically it makes you feel hot and how does it make you feel in other ways?

P: It felt, it make you feel hot, it's where it depends again where you are you feel a bit embarrassed and um… your body, as I said, it feels as if it's not yours… and because your body feels like it's not yours I personally know what is taking place but I don't know what is really in my body but it makes you feel that different and it makes you think sometimes how long is this going to continue… will it continue to the end, will it finish in the next three months, six months or something but that's how the feeling goes, but as I said before these thoughts come to my mind but I don't rest on it, I just accept it… I don't rest on it or make it worry me because depression is not good for me, it only makes things worse, I try not to depress.

I: Mm… and I know you said sometimes it makes you feel embarrassed it depends where you are, which places make you more embarrassed or less embarrassed?

P: Well yeah many times like birthdays or friends who'd invite you to a restaurant or to um wedding reception or weddings and everything like that and you really feel embarrassed because sometimes, many times they would ask you to give a speech or a toast and I will be sitting here, even like in church, you're sitting there and

nothing and as I get up, you just, I could feel it coming on so while I'm up there nobody's sweating but I will have my hanky doing this (gestures wiping face) so you feel embarrassed and my wife says why does he sweat there but not there, and I've looked around and nobody's using a hanky but I am doing it so that's where I feel very embarrassed.

I: Mm…

P: I remember just recently, I'll make this very short, we went to a family dinner, in XXXX it was over there, yeah eleven of us just family and everybody was just eating and I knew it was coming on and just as I could feel it I said no I'm getting up and I got up and went to the loo but then it took longer than I expected and when I came back everybody was there saying I'm waiting for you to eat, I'm waiting for you to eat because yeah you got up, I said oh I'm sorry and they said where have you been so long!

I: So they asked you questions?

P: Yeah they asked questions, where have you been so long, what happened, I thought you missed your way and you couldn't find it to come back… but I just said oh no, no I went to the loo and it took longer than expected, I just did that yeah.

I: Mm… do you think that your flushes affect how you feel emotionally sometimes, do you think it affects how you feel emotionally?

P: Mm… it does, it does… yes I've thought about that, it does… it's not something nice to have, it's not something nice to have…

I: And can you tell me a bit more about that?

P: The flushing?

I: Yeah.

P: Well… (laughs) please do not laugh, because when I explain it to my wife or my family, women have said well you see what I mean when I was telling you about hot flushes, you're going to reach that age still you know where you get hot flushes, so it's similar in the way most of the women reach their… you know what I'm saying yeah, things like that so when I explain to them they said goodness everything's like the same what I tell you, same thing we have I tell you women they have it how I feel and everything it's just the same…

I: Yeah, so who says, what kind of people might say that to you?

P: Uh my wife, my sister and um… only my aunt, those are past the um age for that…

I: And when they say stuff like that, how do you feel when they say stuff like that?

P: (Laughs) well… sometimes I just laugh, I say well maybe I'm a woman (laughs) you know just make a joke and say well maybe I am and I'm going through what you have been through you know… though sometimes when I try to explain it they say oh yes we know, we know what it's like it's a terrible feeling but uh but the only thing about them they said they've already stopped but you're one you don't know when it will stop so…

I: Mm… do you feel like your sweats and your flushes, do you think that they're the same as women's ones?

P: (Sighs) alright I can't tell you what my wife or aunty would say to me, it's hard for me to… how shall I say… express the difference between them because as I say you would know how you feel and how I feel I try to explain but then you would explain to me as much otherwise been caught up there so I think um… my one's a little bit more worse… because one thing, I can't, talking to them, they did not explain, none of them explained to me that when it's coming on they kind of feel it or not so because of what they say is when it's on what they feel like then, but with mine I could tell you when it's coming on so I'm not sure for women if they can tell when it's coming on but they know when it's on what the feeling is like.

I: Mm… and for you, if you were to think about the flushes, is there a worst part to it, so is coming on quite bad compared to having the flush or is having the flush worse than when it's coming on, is there a difference for you?

P: There is a difference, having a flush is worse than when it's coming on… I'll quickly explain… when it's coming on, I'm the only one who'd know but having the flush, depends where you, people can see so there is that big difference there for me, but feeling uh individual feeling inside having the flush is worse to me than when it's coming on because used to it I just smile and say oh yes I'm having a hot flush now and just relax mm…

I: Yeah… and I know you mentioned that you think your diabetes sometimes might affect your flushes, the sweats, do you think there's anything else that might affect them, anything you've identified?

P: No… not really no… because I mentioned that because I want to be careful in what I'm saying because sometimes when you have flushes come and I would check my diabetes, I've got the machine to check it, and I find my reading a little bit high and it's tomorrow now and I've looked at it the next day… I would find that it had come down, that my diabetes is alright, so I could see sometimes it plays a little bit with it but not much… I could just tell you quickly, when my diabetes is a bit high,

the sweat lasted longer, and it lasted longer than when it is um just any other flush so I can't tell then to know which it is…

I: Mm… and do you think there's any um… particular moods that you might be in that could affect them?

P: Yes… that is true… and one of the moods is worry, if there is something that I'm worrying about I could find it comes more regular, lasted longer more than when I'm relaxed, that is very true, depends on the mood that I'm in, if something's wrong or… if for example my wife drives and it's at certain times she should come in, because of the road accident or anything could happen and I knew what time when she left work she would reach home and I look at the clock and she isn't there, the fear just seconds, checking on time you just feel like that… yeah and then that's when it will just come on so it tend to yeah you're perfectly right there it tends to.

I: Okay…

P: Not that I'm watching her you know just to know that what time she comes home and is there any accident she's a bit late today so…

I: Yeah then you feel them come on when you're feeling that?

P: Yeah… so it's that, how do you put it, anxiety? At the time there… any anxiety or something.

I: And are there any other situations like that or different to that, that might cause them to come on?

P: No it would be the same because even if um I'm waiting for my journey call they would ring and say something's um something's wrong or they'll ask me for something that will come on too because… just hearing something that I wasn't expecting…

I: And if, do you think that the flushes affect anything that you do, so do you avoid doing anything because of them?

P: No… no not exactly because anything I'm doing if the flush is there… the moment I know it's coming I can move away that's why cooking, I will be in the kitchen and cooking, I wouldn't be standing up there over the food or anything, wiping, I would move away… wash my hands and things and come back so it won't affect my… the moment that you know it's coming I could move away from it okay…

I: … And would you ever avoid going to a particular place or doing something because of um the flushes?

P: That's definitely… I can assure you that is true several places and it's only recently now that it's, it's not as fluent as before that I take the chance and go out but before I didn't want to leave the house, didn't want to leave the house at all because it came on so regular, I just didn't want to leave so you're perfectly right there… and my wife would say you have to go to the… I said no I don't want to go because I'm just embarrassed.

I: And how often did you used to get them before then, so now it's like three or four a night and then sometimes in the day as well, before what were they like?

P: I think it was up to about five to eight times a night because it was regular then, and whether or not I was going hospital I can't remember now but it was regular.

I: Mm, and what was it like during the day before?

P: In the day it wasn't so much but it still was a lot, I would say about five or six tops.

I: Mm, mm, um and so do you think that having hot flushes has affected how you see yourself now?

P :… No I don't think that no… because it affects my sleep, that's one thing but it don't have to affect you most of the time yeah… and um the only way it would affect me how I see myself now is because um hot flushes keep you awake and you have to get up and watch, wipe and things so for the whole night you may not sleep properly and sweat properly so when you've got to face the morning you wouldn't be looking as fresh and nice as a person who got a proper night's sleep so that's the way it could affect you, with sleep.

I: Mm… and what were you like before you had the flushes?

P: Happy… happy, hardworking… everything that, this is now and before yeah…

I: Mm, yeah… and what are you like now… now that you have the flushes?

P: I tried to work a bit more at home but it's as I said, the going out it one thing that affected me a lot with the hot flushes and where you are, where you're going, it really stopped me, um… I'm not, I won't be scared or afraid of going out because of the hot flushes and things, you're talking to someone like I'm talking to you now, I'm sweating here now, it's not the heat... but then maybe after a while you know it will just cool down… and then you know people say oh you're nervous man, I don't know why you're nervous, why are you sweating… a little bit embarrassing, it is… but as I said before being that there's nothing I can do about it and I understand what it is and what causes it, I have to just accept it and hope for the best…

I: Mm… do you think having hot flushes might have affected how other people see you?

P: Hm… right um most likely being a Christian when I'm with my church brothers or sisters you generally like to give a hug and because of that I would just say to people that I'm sweating I can't go there better shake my hand… so it's affecting the way that people see you… and then when some say never mind man come, come to get a hug and give me the hug that you usually do… some will accept and some will look at you and see you sweating and say oh you're sweating and kind of move away from you, that's a bit embarrassing because you know…

I: Yeah… and do you think it's affected how people see you in any other way?

P: No I don't think so, no…

I: Mm and how much do you think about, do you think about having flushes when you don't have them?

P: When I don't have it?

I: Yeah do you ever think about them?

P: Yes because you're, you think about it feeling glad that you don't but you wonder when it's going to come on again and then when I realise I say to my wife do you notice something, I normally have two flushes from morning and I've only had one and she says oh praise the Lord to hear you say that you know so it, in that time I think you're thinking and wishing it won't come but you, because you have no idea you keep thinking about it… so when it doesn't you know and when it comes you'll still know then…

I: Mm… and how often might you think about them, would you say?

P: No, not really much because when it changes I'm feeling glad, I'm feeling something is good, when it don't happen in that window you're just feeling glad so you don't really keep on about it and then sometimes just like in the evening I say what wait from morning I've only had one or two, so you're not really thinking about it but you know when it comes then you just keep on an idea yeah… so you're not thinking about it, since I've had one or oh I've had two, nothing like that… but because it's all a little bit embarrassing so when you don't have it you feel good and you could tell somebody oh I haven't got it for the last two hours or for half a day or so…

I: Mm… okay and um are there any things that you try to um reduce your flushes or manage them when you're out and about?

P: I stick to the diet, my diet, I stick to the whole diet which is good, I stick to that very, I'm very keen on that and I also, I'm one that I believe in doctors, on what they say to do or not to do so I stick to that too so I do that…

I: Mm… and have they given you any advice about what to do and not to do in relation to the flushes?

P: Y- mm… yes because as I explained before they tried the tablet and it didn't work, they explained that um, my Zoladex injections, it will calm the um hormones down and it will happen so… they just hoped that the cure or something can do it and they just said well how do you feel, that's like what you're asking now, what do you do to stop it or I would tell what I try and everything so there's nothing really that can stop it now…

I: So you feel there's nothing that can stop it now?

P: No, no… unless I think if I stopped taking the injection and then that would make everything worse, because it's coming from the injection, the doctors, I had the doctors explain that to me, because of the injection so… I couldn't stop it now just because of that, it will only make things worse and that injection is what it keeping it from spreading or going to the bone so that's what I'm… it's so good from it so no way would I think of stopping it just for the sweating.

I: … And uh I know you said you stick to the diet, is there a specific diet you've been given that's linked to the flushes?

P: It's um not for the flushes but it's helping everything, a special diet that's helping with the flushing and every little thing so it's better to stick to your diet, you know the starchy food and this and that will only make it worse so stick to your diet will help in every way as the doctor tried to explain, nothing will completely stop it but it will help me flushes, reduce the flushes…

I: Okay… and so um you said like starchy foods and stuff, what have you heard about the foods that could help to reduce the flushes?

P: I just think um… the diet that I stick to for my diabetes that's the one, because as I said if my diabetes is not low it will also will affect my cancer and everything… so I have to keep it, I said that I've been to the doctor and he said what about your diabetes, is it under control, try and keep it under control because with your urine and this and everything and the blood, even with the blood, I don't want to go into details but it is important, if my blood is not level with the diabetes it will affect my um… so I stick to my day, daily diet.

I: Mm… and so how long do you expect your flushes to go on for?

P: Um… I would have thought that, that's what I'm taking from the doctor's answer, but they told me as long as I'm taking this thing it will go on, the doctor also said that after a while it may settle down and it'll come a little less, which I've proved it's true, that as I said before it's not as regular as before but then I can't tell when it will stop because I think when it will stop the doctor said when you don't need no more so then, yeah…

I: So if you're doctor said that you no longer need the injection, do you feel it would stop?

P: Yeah it will stop yeah, I'm sure that it will stop, all the doctors said that it's what causes it so…

I: Mm… okay, so what I'm going to do is I'll say a sentence okay and I want you to just complete the sentence for me okay so, during a hot flush, I am… and then you just say in your own words… so during a hot flush, I am…

P: Just give me a second I'll get it right…during a hot flush I am just… during a hot flush I could just put it, I do not feel like myself… because of how my system in my body feels, I don't feel in my body it just does not feel like myself… until after the flush, then it just comes back normal…

I: Mm, yeah… and during a hot flush, other people see me as…

P: Mm-hm… other people see me as someone who is sick… but do not know the cause of it… people say oh you must be sick or something's wrong with you but they do not know the cause unless I explain to them… so I just usually explain before… … and they would just wonder why you're sweating…

I: Mm… and during a night sweat, so the ones at night, during a night sweat, I am…

P: (Sighs) I could have had this big worry, terrified I'll say… yeah because I know the um circumstances behind that you know to not feel so terrified of it because if it lasted for a longer time I know I'd have to get up and change and mostly lose my nightdress…

I: Mm… and during a night sweat, other people would see me as, so if other people could see you or if anyone sees you during a night sweat, how might they see you?

P: So who?

I: So during a night sweat-

P: Yeah I heard that, the last part?

I: -um other people would see me as, um that's if they could see you or anyone who does see you, other people would see me as…

P: Well other people would be my wife… and um she's a nurse so she has about an idea of what's going on but still the reaction where she would move away it makes me feel, how can I put, very… uncomfortable like yeah uncomfortable because you don't blame her because your body is sweating, it's pouring down and then wetting, nobody wants to come near you like that so… but she's a nurse but she still understands but you know it leaves you, you feel a bit embarrassed, very much embarrassed…

I: Yeah… okay and during a night sweat, what do you think she might be thinking of you… during a night sweat?

P: Well she'll be thinking of me, how long it will be, how long is it going to be like this and um… and she will often say I'm sorry for you not getting your regular sleep like that, sympathise, she's very sympathetic with me often and wonders how long this will be, will it be forever and uh she said it's not for her but it's for me, she can't just imagine how it feel and how I feel…

I: Yeah, mm… okay…

P: And uh sometimes as I say when I'm trying to take off my pyjamas and things and she will say are you dirty, you're not going to get me get my nightdress, you want me to be like you… and uh it's stuck on me so I have to ask her can you help me… and then in the morning she will say look you know I don't mean it but um I'm glad I was there to help you… but she will say let me get some sleep too you know!

I: Yeah.

P: So it's really not comfortable for your partner just like yourself, it's a bit uh embarrassing both ways… but I'm glad she understands it so it, someone who didn't have the experience of maybe working in medical problems would find it worse to um cope with it but she has which is good…

I: Okay… okay and I want to ask you a bit about so what do you, you were telling me that the injections are the cause for your flushes and um do you, before the doctors told you that did you know what the cause was, what did you think the cause was?

P: No I didn't know because the doctor um… after it was given to me that the doctor said to take it then I went back and started telling what the flush is and then they will explain to me what causes it and so I wouldn't know before until when I am telling them how I feel and what's happening to me and then they said uh this is what causes it and we can't stop it, you have to just, sorry, we have to just see how long you can bear it if we try our best to see and that's when they gave me tablets but it didn't work… so they did do their best.

I: Yeah… yeah and yeah I was going to ask so how do you feel about the injections being the cause of your flushes?

P: There's nothing I can do, so I'm glad the injection is helping because it stops my PSA and things so therefore there's a lot of different ways that it's helping and they dare not stop that now, so I just take it as… as it comes… I just don't let it worry me no more because I know it's, it's doing me good… and I got no time, no doubt that ever come in my mind that thinking I said should I go to the doctor and tell him stop it now I can't bear it no more, although it's embarrassing, I have to, I just live with it and… sometimes I just ignore it as nothing, I just ignore it as nothing because I know it, there's nothing I can do.

I: And when you said you know, did you say sometimes you think should I go to the doctor and stop it, the injection, did you say you sometimes think that?

P: No I have never thought that, I said um I do not think that uh thought I would go to the doctor and ask them to stop it after they said to me what it would do…

I: Yeah, yeah… and how do you think your flushes have been managed by the people around you like doctors and nurses?

P: Yeah, yeah they're good, they're very concerned but they're experienced, they're very experienced and I'm not the only one so maybe so many times over the week or the month people say they come to them and they explained to me there's nothing they can do, we had a patient last week and he had more flushes more than you and everything so you have to just cope with it we're doing our best, so they will know what is going on and they are doing their best but they are, I don't think there is something that they can do that they have not been doing…

I: And what about your friends and family, how are they managed by friends and family, your flushes?

P: That again I make sure that all my family know about it… and uh they all sympathise and accept, a lot just accept it and I sympathise uh knowing about it that it's cause this question and this thing they just sympathise um… and when they say I could see you sweating again but it doesn't mean nothing really, they just pointing it out… so I make sure that my family know about it, but um quite a lot of Christians as I said before they don't know about it it's better than some know, they will pass it on, how come you never tell the cause of it all, so I just make sure everybody knew about it…

I: Mm…

(Pause)

I: Okay and um, when you had the tablets so did you have uh the tablets for the flushes, what did you think of the treatment?

P: With the tablets?

I: Yeah.

P: It didn't make no… progress at all, it didn't do nothing, it didn't try to stop it or nothing, and um… it kind of made my body feel different, but if it had made my body feel different and was helping me I would have continued but it didn't help, it wasn't helping at all, no time did they say well, checked it out trying to help, it didn't do no good, as I was told by the doctor before I tried it, they doubt it but um when I took it people said it depends, they said it may help but it didn't help me so I just said it well quickly that it's not helping so useless to stay on it.

I: Mm and when you say it made your body feel different but it didn't help, how did it make you feel different?

P: Well I could tell when you take the tablet it's not the same feeling in your body when you don't take it, more like when the hot flushes come now something you know the tablets you take it can feel like that and then after a while it goes down after an hour and a half or something but you know it's the tablet that makes you feel like that because before you took the tablet, it was a different feeling and then you took the tablet you feel something.

I: Yeah… and when it didn't work, what were your thoughts when it didn't work?

P: Well as I said before the doctor already explained that it may be a while you have to take it for before you know you come back and say it helped but this is what the people do to try to help so I do try and let them know how you got on with it and so on so I don't know, I don't think the little that I… see if it were like 50-50 or 75-25 nothing you're just sitting but the other people said it doesn't help so I could try it, I just can't remember the name of it because that was quite a long time, I don't remember the name of it now…

I: Yeah that's alright… um… and um do you know of any other treatments for hot flushes, have you been made aware of any other treatments?

P: … No, no… no I wasn't told by the doctor, I was told by people I know had it before, I don't know if they have treatment or…

I: And would you be interested in another treatment option if there was one out there?

P: Yes ones that would make it better yes, I'm quite willing to try because you're not sure once you take it… if at the end you have to choose between which of them are

best I would have to choose which one helped me the most because it could be any one of them… but I would be willing to try if there was something but you know that um as the years go by scientists coming forward with this and that can help, some of them proven some not proven so you won't be sure until um… but even they themself not sure sometimes they come out and say this is that and by next month they say oh no no don't do that, don't do that…

I: And I know on one of the questionnaires, there was a preference for kind of a treatment options so if you could choose a treatment which would you choose and you chose medication and there was options like a group to manage night sweats or hot flushes and a self-help guide to manage hot flushes and night sweats, what do you think of the other two, a self-help guide or a group?

P: If that could be proven to me first, if it can be proven to me first because if it has been proven and I could, I would um I trust the doctors that it has been proven, four or five people said they… then I would I won't take the chance until it has been proven…

I: And if there was like a self-help guide, like a booklet or a CD that someone could give you that said try this, this has worked for this number of people, would you, would you be interested in that?

P: Yes, I would try, I would try.

I: And which sort of format would you prefer, would you prefer like a booklet or a CD or would you prefer to see somebody on a regular basis and talk with them about what you've tried?

P: No a CD would be good because I could play back and back and if there's something there that um I don't understand or like I could come here to contact somebody and say that… I think the CD would be alright, to see someone would be too many times but the CD you could play it ten times or five times that day if you want to…

I: Okay… and um when you talk about flushes or if you were going to a group or something to talk about flushes would you prefer if you were talking to males or females, do you have a preference?

P: … Whichever one would understand it better (laughs)… uh I'm comfortable speaking to a female not because I'm a man, I seem to be get on more with the female, more than male… some people will say well because I'm sick I'll want a female but I'm only because you can explain to them and tell you how I feel or what is going on… so coming in and seeing a female here, a male and a female, you have to choose I think I'd choose a female because I, I've no need to continue explaining… I think the females seem to be a bit more understanding more than the

males, that is to me seem to be a bit more understanding, interested, they show more interest in things more than the male because you could be telling one... oh yeah, yeah, whereas the female you've got to let it out and see what's coming out.

I: And with the group option, if it was like a group of other men who also have hot flushes and you're all talking about what helps and giving advice about what helps or not, what would you think of something like that?

P: I think it would be good, that would be good because one thing they explain it all coming in, one or two men a bit similar but when it's one or two men have something not the same, and to pass it along and say when or how or what, how he copes with it, it would be good, I would like to hear that the difference between my feeling and what they're feeling…

I: Yeah… okay well good those are all of the questions I wanted to ask you that's everything um is there anything that we've not covered yet that you would like to say or ask?

P: Let me just think roughly... no I uh what you've done there I really understand that and if it will go and help others or help the nurses or the doctors with three of those brains together against one, then this thing that I gave you maybe twenty persons gave the same thing it will help that nurse and the doctor to know or the scientists to… so… and that's why I'm glad to come along because I'm not selfish, if I can help somebody with it by passing my feeling it can help somebody or even to comfort somebody maybe it don't help them but they say okay somebody has the same feeling but he's happy with it and he's surviving, that's why I'm here so…

I: Well on that basis so the other question is sort of do you think the interview has captured your experiences of your hot flushes and your night sweats?

P: Yes.

I: Um and I wanted to say that I'm hoping to put together a report and if you are happy to have the results from it and that would just mean giving you a summary of what other men have said who I have interviewed as well and it will include what everyone has said but without any names or anything it's completely anonymous-

P: That would be good.

I: So you would be able to hear about some of the other men's experiences.

P: That would be good I could compare it to mine and I think where mine is different or is contrary to that one and I could see well that one is not telling the truth or the difference between… that would be good.

I: Yeah, would you be happy to have that report?

P: Yeah.

I: So I can send that to you in the post, so I'm hoping to submit this for research like you say to try to help the prostate cancer group of men so this will probably take a little while before you get this report so probably next year after May.

P: Oh I can wait, yeah, yeah I'll have to read it… I think that will also strengthen me and encourage me to realise me to that I'm not the only one, there are other people and so like the other men who do it they'll say hey this guy has the same thing like me you know…

I: Okay and finally before we finish there was just one other thing I wanted to ask and I asked you about triggers and what you think affects your flushes, I wondered if you thought there were any specific triggers or anything that triggers them off apart from anything you've already said?

P: No… I… actually think anxiety or stress and that as I say to people I'm sure that will have, the whole thing, you have anxiety and you are scared or you are afraid of something and you just go but there's feeling from that now I'm just thinking but I think anxiety and stress, and if you're a bit frightful, then yeah because um I know on one occasion I just had a sweat or flush and I heard that um my aunty died whom… I just got a phone call, I had a phone call but I was seriously caught up at that, how would you call it, at that moment, but that again it's only occasionally that happens, that's nothing regular.

I: Mm, okay, alright well good so that's everything I wanted to ask so that's where we'll end.